‘WE’RE ALL GETTING OLDER YOU SEE, AND THINGS DO CHANGE, DON’T THEY?’

D. DE WAAL

PHD

2018

‘We’re All Getting Older You See, and Things Do Change, Don’t They?’

An Ethnographic Study of Disruption and Continuity in the Daily Lives of Couples Living with Dementia and Co-morbidities

Denise DE WAAL

Submitted for the Degree of

Doctor of Philosophy

Faculty of Health Studies

University of Bradford

2018

Abstract

Denise De Waal

‘We’re All Getting Older You See, and Things Do Change, Don’t They?’

An Ethnographic Study of Disruption and Continuity in the Daily Lives of Couples Living with Dementia and Co-morbidities

Keywords: dementia, co-morbidities, spouse care, ethnography, habitus, identity, continuity, medical anthropology

Most people with dementia live in the community with a family member, commonly a spouse. Together they engage in identity redefinition to maintain continuity. Many people living with dementia also have co-morbidities. The aim of this study was to provide a better understanding of the influence of co-morbidities on the lived experience of couples and to provide knowledge to improve services. This had not been researched before.

Drawing on the dialectic relationship between the body, habitus, environment and common sense from Bourdieu’s theory of practice (1977; 1990) combined with identity theory as described by Burke and Stetts (2009) I conducted an ethnographic study with five couples over a six-month period.

The resulting data were analysed using a framework approach and are presented using case studies to illustrate key points. Drawing up on the data I developed an identity perspective which provides a better understanding of these couples’ daily life experiences taking into consideration the contextuality of people’s multiple identities, experiences, care and support needs and their interaction with the environment and community. My findings illustrate how people with dementia and co-morbidities and their spouses negotiate their identity in daily life in order to continue their daily life routine and cope with health conditions. Furthermore, these identity negotiations influence the acceptance of the diagnoses of dementia, the

access to care, services and information and the experience of dementia, stigma and co-morbidities in daily life.

Implications include a presentation of the limitations of current concepts of embodied selfhood and the *Aging in Place* policy for people with dementia. It points to the potential of the identity perspective to shape policy, services and care practice consistent with couples' lived experience and their needs and preferences.

Dedication

Voor oma Anneke en oma Marie
To grandma Anneke and grandma Marie

Graag draag ik deze thesis op aan jullie. Jullie herinnerden mij er altijd aan hoe belangrijk het was om mijn best te doen op school. Zelf hadden jullie immers nooit de kans gehad om door te leren. Het voelt speciaal om twee generaties verder te kunnen zeggen dat ik kan promoveren aan de universiteit. Bedankt voor jullie motiverende woorden en steun, deze thesis is ook een beetje van jullie.

I would like to dedicate this thesis to my two grandmothers. They were born and raised in a time and place where and when they had no opportunities to be educated. They always told me it was important to work hard at school, education is valuable, especially since they never had the chance to enjoy it. Two generations down the line I am able to study for a PhD. I would like to thank them for their motivating words and support.

Acknowledgements

First of all, I would like to thank all the participants in this study for letting me into their lives and sharing their experiences. Thank you for sharing all those emotional, enjoyable and difficult moments with me. I am happy I had the chance to get to know all of you.

I would like to thank the Alzheimer's Society for providing the funding for this study and for their belief in me as a future dementia care researcher.

I would like to thank my supervisors Professor Murna Downs and Professor Neil Small for giving me the opportunity to do an ethnographic study drawing upon medical anthropology within a department where such a research approach had not been used before.

I would like to thank my experts by experience, the carer reference panel and the stakeholder group for their advice, support and input in the different stages of the study.

I would to thank the members of the international expert panel of the DTC and especially Professor Myrra Vernooij-Dassen and Professor Martina Roes for their advice on my project and their invitation to visit their research groups at the University of Nijmegen and the University of Witten.

I would like to thank my friend and fellow PhD student, Natash Lemmos-Dekker from the University of Amsterdam for her support throughout the thesis and providing me with the opportunity to visit and present at the University of Amsterdam.

I would like to thank my friend and fellow anthropologist Dr Matthew Lariviere from the University of Sheffield for our Skype sessions on ethnographic fieldwork experiences.

I would like to thank the medical anthropology research group at the Free University in Berlin, especially Professor Hansjoerg Dilger, for offering me the opportunity to visit their institute for two and half months to improve my ethnographic writing skills.

I would like to thank the EU for providing me with an Erasmus+ grant to visit the Free University in Berlin.

I would like to thank my fellow PhD students of the Doctoral Training Centre on Transitions in Dementia Care at the University of Bradford for their peer support throughout the project.

Table of Contents

List of Figures

Photos Taken by the Participants as Part of their Photo Diary (A)

** The couple themselves labelled photos 2A, 10A and 12A in their photo diary.*

Photos Taken by the Researcher (B)

Chapter 1

Introduction:

The number of people living with dementia worldwide is expected to rise to 131.5 million by 2050 (Prince 2015). All these people will need specific care and support, which impacts on the economies and societies of countries. Dementia was called a 'World Health Priority' by the World Health Organization in 2012 (WHO, 2012). The government in the United Kingdom has launched a Prime Minister's Challenge on Dementia in 2012 and again in 2015, making dementia care one of the priorities of health care policy (DoH, 2015; TeamDementia, 2012). Their aim is the following: 'Our vision is to create a society by 2020 where every person with dementia, and their carers and families, from all backgrounds, walks of life and in all parts of the country – people of different ages, gender, sexual orientation, ability or ethnicity for example, receive high quality, compassionate care from diagnosis through to end of life care' (DoH, 2015:5).

Two-thirds of all people living with dementia live in the community and many of these people are being cared for by a family carer, such as a spouse (Alzheimer'sSociety 2014). Providing high quality care and support to these spouses is important to the government because they promote 'ageing in place', especially for people living with dementia. (Sixsmith and Sixsmith 2008; Ridley-Ellis 2011; JSNA 2015; NHS 2015; Volpe 2018). To be able to provide this type of tailored support we need to understand better what support and services are needed in people's daily lives.

There is a body of literature on spouse care in the community that looks into the daily life experience of co-habiting spouses of whom one has dementia, but there are multiple gaps in the existing knowledge. An important gap is the lack of studies that include a focus on the influence of co-morbidities on the lived experience of these spouses. The prevalence of co-morbidities among people who have dementia is high (Doraiswamy et al. 2002; Scrutton and Urzi Brancati 2016). Some research even suggests that seven out of ten people with dementia also have co-morbidities (APPG 2016). These co-morbidities in combination with the dementia complicate the management of the health conditions (Mountain and Craig 2012; Newbronner et al. 2013). This more complicated care situation means that these spouses may need

more care and support. Therefore, how co-morbidities influence the daily life experience with dementia for spouses in the community is an important area for research.

My personal interest in doing research into the lived experience with dementia comes from a summer job I used to have in a Dutch nursing home, in a ward for people with dementia. I worked alongside my mum who still works there and we often talked about the work and the experiences of the people with dementia and their relatives. I decided I would like to understand better the daily life experiences of people with dementia and their relatives.

The aim of this project was twofold: to gain an understanding of the daily life experience of co-habiting spouses in the community in England, of whom one has dementia and co-morbidities, and to provide knowledge to improve services for couples such as these. The research question was: How do dementia and co-morbidities influence the daily life experience of co-habiting spouses in the community in England?

The existing literature on the lived experience of spouses in the community of whom one has dementia is mostly explorative and has identified changes and processes that couples experience and the meaning they give to these experiences. Furthermore, it has identified some possible strategies that couples use to cope with these changes and processes. Nevertheless, it has failed to analyse these changes and processes. There is a need for explanatory research that provides a better understanding of these changes, processes, coping strategies and the way spouses give meaning to these experiences.

In this study I used an explanatory research approach drawing upon a holistic theoretical framework based on the dialectic relationship between the habitus, common sense, the body and environment as described by Bourdieu in his theory of practice (1977; 1990) combined with identity theory as described by Burke and Stetts (2009) and interpretative ethnography (Boeije et al. 2009). I conducted six months of fieldwork with five couples, of whom one partner has dementia and co-morbidities and the other partner is the primary carer and they live together in the community in North England. During this fieldwork I collected data by conducting informal interviews, semi-structured interviews and life history interviews, keeping field notes, doing participant observation and using photo diary methods. I analysed the data using framework analysis.

In this thesis I will present the background of the study, the theoretical background, the study design, the ethnographic data including a discussion of relevant literature, a reflection on my experience in the field and the research process and a discussion and conclusion including a discussion of possible implications for care. In chapters 2 and 3, I will provide the background of the study, the theoretical framework and study design. In Chapter 2 I will give the background of the study by presenting a systematic synthesis of the existing literature on the lived experience of spouses in the community, of whom one has dementia. Furthermore, I will discuss the existing knowledge on dementia and co-morbidities. In Chapter 3 I will discuss the methodology used, theory, research design, research questions, aims, objectives, validity, reflexivity, triangulation, saturation, the sample, recruitment strategy, methods of data collection, the data analysis process and the ethical considerations.

In chapters 4 to 7 I will present the ethnographic data and a discussion of relevant literature. These chapters consist of a presentation of the ethnographic data organised by theme. They all have the same structure: an opening vignette, a short overview of relevant literature on the theme, and a presentation and discussion of the relevant ethnographic data. The theoretical framework and its concepts are used differently in the different chapters. The framework is used as analytical tool throughout these chapters but the most in-depth use and discussion of the concepts from the theoretical framework in relation to the data is found in Chapter 6.

Chapter 4 discusses the way that dementia and co-morbidities are intertwined with daily life. Chapter 5 discusses the existing stigma surrounding having dementia and how this influences different aspects of the couples' daily lives and identities. Chapter 6 focusses on each couple's relationship, their individual identities and how these aspects influence the challenges they experience in their daily lives. Chapter 7 illustrates how these identities and daily lived experiences are embedded in and tied to broader social relationships like the family and community.

In Chapter 8 I will present my reflection on being in the field and the research process. It presents some ethnographic data but in connection to the researcher's reflection on designing the project, being in the field, leaving the field, analysing the data and writing up the results. The aim of this chapter is to provide an overview of the high level of reflexivity used throughout the study.

Chapter 9 is the final chapter, it provides a discussion and conclusion that considers all the different themes presented in the separate chapters and a reflection on, the contribution of the study to current knowledge, the used methods and methodology, the strengths and limitations of the study, possible future research, and the possible implications an identity perspective could have for rethinking current services and support for people living with dementia and co-morbidities and their partners in the community.

Chapter 2

‘We’ & ‘I’, ‘Sustaining Couplehood’

Background: Spouse Care, Dementia & Co-morbidities

2.1 Introduction

As discussed in the introduction of the thesis, most people who have dementia also live in the community and are being cared for by a family carer, such as a spouse (Alzheimer'sSociety 2014). Many of them also have co-existing health conditions, co-morbidities (APPG 2016). In this chapter I will show that there is a need for research into the lived experience of these couples in the community.

First, I will present the results of my systematic search and appraisal of the spouse care literature on co-habiting spouses caring for their partner with dementia. One of the gaps this literature review revealed was a need for research on the lived experience of these spouses that takes into account co-morbidities. For this reason, I have decided to present some of the current knowledge on dementia and co-morbidities. Finally, I will provide a small summary of the chapter and introduce the topic of Chapter 3.

2.2 Systematic Synthesis of Spouse Care Literature

2.2.1 Search Strategy

The aim of this review was to look at the current knowledge of the lived experience of couples in the community who live in first-world countries, of whom one has dementia and the partner is the primary carer, and to identify gaps and possible opportunities for future research.

To accomplish the aim, the following search terms, inclusion and exclusion criteria and search engines were used:

2.2.2 Search Terms

(Couple OR Spouses OR Partners OR marriage OR Couplehood) and (Dementia OR Memory Problems OR Alzheimers)

((Couple OR Spouses OR Partners OR marriage OR Couplehood) and (Dementia OR Memory Problems OR Alzheimers)) and (at Home)

((Couple OR Spouses OR Partners OR marriage OR Couplehood) and (Dementia OR Memory Problems OR Alzheimers)) and (Informal Care)
((Couple OR Spouses OR Partners OR marriage OR Couplehood) and (Dementia OR Memory Problems OR Alzheimers)) and (at Home and Informal Care)
(Couple OR Spouses OR Partners OR marriage OR Couplehood) and (Dementia OR Memory Problems OR Alzheimers) and (Co-morbidity OR Co-existing Illness OR Chronic Illness)

2.2.3 Inclusion and Exclusion Criteria

2.2.3.1 Inclusion criteria

- couples of whom one has dementia
- partner cares for the person with dementia
- community dwelling
- focussed on their relationship
- qualitative research
- peer reviewed paper
- the papers need to focus on the relationship of the couple, of whom one has dementia (or it can be defined as memory problems or Alzheimer's) and the partner is a spouse carer, their daily life experience: This can include subthemes about intimacy, health management, the acceptance of social care (as long as it is researched from the perspective of the service user), the home environment they share
- written in English or Dutch

2.2.3.2 Exclusion criteria

- grey literature
- personal testimonies
- reviews
- commentary papers
- intervention studies
- clinical trials
- randomised trials

- studies based on quantitative methods and or design; for example, an experimental design
- studies that have a biomedical or psychosocial focus; for example, a focus on stress levels or measuring cognitive abilities, psychological wellbeing, measuring health, etc.
- studies situated in institutionalised care
- studies about formal care support from the perspective of the care organisation, its workers
- studies about general health care policy
- studies focussed on research methods; for example, the development of new tools
- studies that only include the person with dementia as a participant and do not include the spouse care relationship
- studies situated in countries that do not have a similar level of health and social care to the United Kingdom
- studies focussed only on diagnosis and/or disclosure
- studies focussed only on decision making
- studies including spouse carers of partners who do not have dementia; for example, studies that compare the caring experiences of spouses of partners with different health conditions, not necessarily dementia
- studies including other family carers than only spouse carers

There was no cut-off date for inclusion and or exclusion of articles because the discourse of dementia care is relatively young. Moreover, a research focus on the relationship of the couple is a recent development. As I will show in the broad overview of dementia care discourse in Chapter 3, this focus only started to enjoy attention after Kitwood's development of person-centred care twenty-five years ago (Kitwood and Bredin 1992).

2.2.4 Search Engines Used and Dates of Searches

ASSIA: 03/02/2017

ScienceDirect: 08/02/2017

MEDLINE: 10/02/2017

CINAHL: 13/02/2017

Scopus: 13/02/2017

Update Systematic synthesis on 24/07/2018
ASSIA: 24/07/2018
ScienceDirect: 24/07/2018
MEDLINE: 24/07/2018
CINAHL: 24/07/2018
Scopus: 24/07/2018

Original search results produced by the search engines in February 2017: 2337 articles. At the time of the update in July 2018: 262 additional results were found. Three different rounds of exclusion were used:

2.2.5 Selection Rounds

2.2.5.1 Selection round 1 (n=2337)
Update 24/07/2018(n=262) total (n=2599)
Based on the titles of the articles and the journals they were published in, I excluded 2358 articles. The main reasons for exclusion were: a language other than English or Dutch, duplicates and titles indicating a study design that should be excluded according to the criteria. Some of the article titles communicated that the article discussed a clinical trial, a randomised trial or an intervention study, took place in institutional care or focussed on the perspective of the formal care provider or its employees or a policy perspective.

2.2.5.2 Selection round 2 (n=236)[1]
Update 24/07/2017 (n=5) total (n= 241)
From reading the abstracts and selecting based on the inclusion and exclusion criteria, I excluded 217 articles. A list of the excluded articles and reasons for exclusion can be found in the Appendix.

[1]Find a list of the excluded articles in appendix 1.4

2.2.5.3 Selection round 3/critical appraisal (n=22)[2]

Update 27/07/2018 (n=2) total (n=24)

The Critical Appraisal Tool used is the CASP (Critical Appraisal Skills Programme) qualitative checklist (CASPUK 2018). Six articles were excluded due to multiple quality issues; for full list see Appendix. The number of articles included in the systematic review is 18 (n=18).

2.2.6 Introduction to Systematic Synthesis: Lived Experience

Eighteen articles were eventually included, all focussing on the lived experience of the couples. After analysing the included articles, I identified two overarching themes within this lived experience in the articles, namely: relationship and identity. The theme of relationship includes the subthemes disruption and continuity, change in role patterns and meaning; the theme of identity includes the subthemes gender and cultural background.

Nine articles focus on the relationship of the couple, describing and/or discussing the experience of living with a partner with dementia, either solely from the perspective of the carer or from the perspective of both spouses (Murray et al. 1999; Jansson et al. 2001; Daniels et al. 2007; Hellström et al. 2007; Vikström et al. 2008; Walters et al. 2010; Beard et al. 2012; Botsford et al. 2012; Sinclair et al. 2018). Five articles describe and/or discuss the changes in role patterns in the relationship and the couple's response to it (Clare 2002; Vikström et al. 2005; Brown et al. 2007; Boyle 2013; Boyle 2014). The other four articles focus on exploring the meaning of caregiving within the relationship (Paun 2003; Eriksson et al. 2013; Shim et al. 2013; Bergman et al. 2016). Eight articles include a focus on identity (Murray et al. 1999; Jansson et al. 2001; Paun 2003; Brown et al. 2007; Botsford et al. 2012; Boyle 2013; Eriksson et al. 2013; Boyle 2014). Five articles focus on the influence of gender identity on the lived experience (Paun 2003; Brown et al. 2007; Boyle 2013; Eriksson et al. 2013; Boyle 2014). Two articles focus on the influence of cultural background on the lived experience (Jansson et al. 2001; Botsford et al. 2012) and one article focusses on both (Murray et al. 1999).

[2] Find a list of the excluded articles in appendix 1.3

First, I will discuss the theme of relationship as part of the lived experience and its subthemes, disruption and continuity, changes in roles and meaning. Secondly, I will discuss the importance of identity in how daily life is experienced by these couples, focussing on gender and cultural background.

Afterwards, I will discuss the methods used, methodology and limitations of the included studies, followed by a representation of the implications of practice as suggested in the articles. Finally, I will discuss opportunities for future research and what kind of research could contribute to the field of spousal caregiving for someone with dementia in the community, and show how my study sets out to do so.

2.2.7 Relationship

There was a diversity of main findings in the studies, but one of the topics that was discussed in most of the studies was the main finding of the study of Botsford et al. (2012): all couples go through a redefinition process of their relationship when one of the spouses develops dementia (Walters et al. 2010). Hellström et al. (2007) and Beard et al. (2012) have identified three phases in this redefinition process: 'sustaining couplehood' followed by 'maintaining involvement' and finally 'moving on', which can result in maintaining the continuity and becoming 'we', or creating distance between the two, becoming 'I' and seeing this as a 'new beginning'.

The literature describes that this redefinition process is triggered by changes in the person with dementia, changes in the reciprocity, changes in the ability to have a conversation, a change in ability to make plans for the future (Walters et al. 2010; Sinclair et al. 2018), changes in role patterns, possible changes in the acceptance of external support (Jansson et al. 2001; Daniels et al. 2007; Botsford et al. 2012), changes in involvement in activities (Vikström et al. 2008) and changes in decision-making processes (Sinclair et al. 2018).

A spouse carer will experience challenges in reciprocity (Walters et al. 2010) and dilemmas related to fulfilling his or her own needs and the needs of the partner. This can cause power imbalances (Jansson et al. 2001; Vikström et al. 2008; Walters et al. 2010). The change of power balance is also expressed in the full-time responsibility of caring, always being tied to the caring. Additionally, carers become mediators between the person with dementia and others in their social network, including formal caregivers and family members (Jansson et al. 2001; Walters et al.

2010). While carers have to take up this role as mediators they also experience a reduction of social contacts (Vikström et al. 2008).

2.2.7.1 Disruption and continuity

A sub theme of the lived experience of couples is disruption and continuity. We cannot simply define caring for a spouse with dementia as a stress, a burden or a disruption; this neglects the dynamics within a couple (Daniels et al. 2007; Hellström et al. 2007; Botsford et al. 2012) This dynamic which informs the couple's narrative is also influenced by the couple's family, social support, life evaluation and perceptions about the future (Daniels et al. 2007).

The responses to the partner's dementia can be diverse, and different symptoms of the dementia can create varied responses, (Murray et al. 1999) such as feeling guilty, having empathy, gaining a sense of acceptance and feeling challenged (Walters et al. 2010; Botsford et al. 2012). A sense of continuity in the understanding of and response to the partner's dementia creates a better adjustment to caregiving (Walters et al. 2010). The creation of a sense of continuity is also illustrated by the fact that many couples accept the changes in health and relationship as expected due to old age and its associated decline (Botsford et al. 2012). This might be related to some couples' 'lifelong commitment', which might be based on their shared past (Daniels et al. 2007) or a sense of duty, an obligation to care (Murray et al. 1999). The continuity and commitment can be sustained in different ways: talking things through, being affectionate and appreciative, making the best of things (Hellström et al. 2007), working together (Vikström et al. 2008), fostering companionship (Murray et al. 1999) and creating dignity and value for the spouses. These ways of creating commitment will eventually enable the spouses to age well and stay at home longer (Beard et al. 2012).

2.2.7.2 Changes in roles

Part of the lived experience and the redefinition of the relationship are the changes in roles. These changes are at the core of the change in the dependency relationship which lead us to question agency, power balance, independency and identity which I will explain in this section.

In Clare's (2002) study in which she interviewed twelve people in the early stages of dementia and their spouse carers about how they coped with the changes they were experiencing ,most of the coping strategies that were mentioned to divide the roles in the couple were focussed on a positive outcome of the self. The coping strategies were based on finding an equilibrium between being able to adapt to the changes in roles and perhaps redefine what a role entails and being able to accept help to carry out a role. This equilibrium could reduce the frustration of the spouse with dementia and/or improve their self-esteem (Vikström et al. 2005).

The adjustment to the change in roles is a process in which both spouses are involved. Clare (2002) speaks about four different phases that a couple goes through before arriving at the equilibrium: holding on, compensating, fighting and coming to terms. Different stages include different coping mechanisms. The caring spouse plays an especially important role in this process as an enabler for adaption of the roles and tasks, supporting the spouse with dementia to do the tasks. Vikström et al. (2005) speak about two types of support: practical support and adapting the environment to the needs of the spouse.

Vikström et al. (2005) also examine the negative aspects of the given support, like providing insufficient support, inappropriate support or no support at all. Boyle (2013; 2014) shows in two articles from the same study how factors other than the loss of abilities influence the negotiation of this equilibrium. Spouses of people with dementia sometimes exclude their spouse from the decision-making process while the spouse still has the ability to make decisions. Shows how the decision making between the couple is a reflection of the changes in their relationship they are experiencing (Sinclair et al. 2018).

Furthermore, Boyle argues that, for women with dementia, not only the loss of abilities but also their gender undermines their agency. Some men in Boyle's study refused to support their wife to enable her to keep cooking, even when sustaining that role would help her to maintain her identity and selfhood (Boyle 2014).

Not only does the spouse with dementia have to accept that they might not be able to perform a certain role, their partner who has to take over certain roles might not be able to do so either. In these circumstances, spouses have to accept external help. The accepting of external help is another process in which an equilibrium has to be established as to the type and level of support they are willing to accept. Brown

et al. (2007) explain how different factors and conditions, such as attitudes, values, experiences, economic means and availability, can work as barriers or facilitators in the help-seeking process. When external help is not obtained when it is needed, negative effects on the physical and mental wellbeing of the couple can develop (Brown et al. 2007).

After presenting descriptions of the lived experience and indicating changes in the relationship of the couple and the renegotiating of the roles, we now look at the meaning these processes have for the couples.

2.2.7.3 Meaning

Two studies explored how female carers give meaning to caring for their male spouse with dementia. According to Eriksson et al. (2013) female caregivers refer to heteronormative and gender expectations to give meaning to the caring.

The female caregivers in the study of Paun (2003) did not necessarily find meaning in their gender identity and expectations but in keeping a positive outlook on their situation, acknowledging their losses and counting their blessings. They felt empowered in being able to make the decision to care for their spouse by themselves, taking ownership of the role and being determined to keep this role as long as possible. They were motivated to hold on to the marriage whether it had been good or bad in the past.

Shim et al. (2013) showed how not only female carers but also male carers found meaning in the caregiving by creating a determination to fulfil the caring role. Although the experiences, circumstances and situations of carers in their study varied, all of the caregivers found the motivation and meaning to care in the values and ethics they believed in. These values and ethics not only fostered determinism but also guided their decisions.

One study not only explored the meaning that the caring spouses give to their caregiving and daily life with a spouse with dementia but also included the perspective of the spouses with dementia. The perceptions of life of both spouses change when one of them develops dementia. Especially, perceptions of the future, space and time change by confronting the couple with a changeable past, present and future (Bergman et al. 2016). Bergman et al. (2016) conceptualise these changed perceptions as a changed ‘lifeworld’ fostering ‘unhomelike’ feelings, suggesting that the meaning of life changes for both spouses and a sense of

restriction develops as the situation creates boundaries. Also, there is a change in the meaning of being together. They draw upon the concepts of Heidegger but fail to translate these concepts well to the real world, which makes it difficult to understand the exact meaning they try to communicate.

2.2.8 Identity

2.2.8.1 Gender

Different studies include an analysis of the influence of gender on the lived experiences, change in role patterns and the giving of meaning. Four articles clearly focus on analysing the influence of having a female gender identity (Boyle 2013, 2014; Eriksson et al. 2013; Paun 2003), one article focusses on the influence of male gender identity on help-seeking behaviour (Brown et al. 2007) and one article explores the influence of both gender identities on the experience of caring for a spouse with dementia (Murray et al. 1999).

Three articles that look at the influence of the female identity on the roles and meaning of caring conclude that gender plays a big part in the division of roles and the meaning that is experienced by couples and/or female carers (Boyle 2013, 2014; Eriksson et al. 2013). Eriksson (2013) speaks of a hetero polarisation (a clear distinction in gender identities based on heteronormative expectations and role patterns) in couples with the woman as the caregiver created by the illness of the spouse and the caregiving duties. Boyle (2013, 2014) argues that women are in a disadvantaged position because not only their abilities but also their gender identity undermines their agency.

All three studies lack a critical exploration of other factors that could create the effects they described. They seem to ascribe experiences to a gender identity without a clear argument as to why the experiences could not be caused by other factors. One of the conclusions of the study of Eriksson et al. (2013) is that women downplay the need for external help, but we can question if they downplay this need because of expectations, values and ideas we have about what a woman should do in a marriage or whether there are other, non-gender related, factors which can explain this. All the three studies set out with an aim to explore the influence of gender on the experience; this could potentially create a bias, but the studies do not clearly reflect on such a bias(Boyle 2013, 2014; Eriksson et al. 2013).

Brown et al. (2007) came to the conclusion that support needs of husbands differ from those of wives. This is a problematic conclusion since the support needs or help-seeking behaviour of wife carers is not explored in the study and the experience as explored in possible other studies is not included. This lack of information makes it difficult to understand what part of the caregiving experience presented in the study can solely be ascribed to the male gender identity.

In contradiction to these results, Murray et al. (1999) conclude in their study that there is no difference in how male and female carers experience caring for their spouse with dementia. Another aspect of identity that influenced the daily life experience is cultural background.

2.2.8.2 Cultural background

Some researchers suggest that spouse carers have remarkably similar subjective experiences of caring even when they come from different cultural backgrounds or live in different countries (Murray et al. 1999; Jansson et al. 2001), while others, like Botsford et al. (Botsford et al. 2012), argue that ethnicity influences the experience of caring for a spouse with dementia. Greek-Cypriot and African Caribbean partners may delay their request for support in the caring and might have different preferences in their decision for family or formal care.

2.2.9 Methodology, Methods, Limitations and Future Research

Eight papers included only the spouse carer as a participant (Botsford et al. 2012; Brown et al. 2007; Eriksson et al. 2013; Jansson et al. 2001; Murray et al. 1999; Paun 2003; Shim et al. 2013; Walters et al. 2010).The other ten papers included both spouses as participants (Beard et al. 2012; Bergman et al. 2016; Boyle 2013, 2014; Clare 2002; Daniels et al. 2007; Hellström et al. 2007; Sinclair et al. 2018; Vikström et al. 2005; Vikström et al. 2008). Fourteen studies used interviews (Beard et al. 2012; Bergman et al. 2016; Botsford et al. 2012; Brown et al. 2007; Clare 2002; Daniels et al. 2007; Eriksson et al. 2013; Hellström et al. 2007; Murray et al. 1999; Paun 2003; Sinclair et al. 2018; Shim et al. 2013; Vikström et al. 2008; Walters et al. 2010). Of all the studies using interviews, only two studies included their interview questions in the paper (Botsford et al. 2012; Paun 2003); this is a quality issue for all the other interview-based studies.

Two studies used observations (Jansson et al. 2001; S. Vikström et al. 2005); both of them lacked an observation guide. Finally, two studies used interviews and participant observations (Boyle 2013, 2014); these studies also lacked an observation/interview guide. Moreover, most studies also did not use reflexivity and failed to clarify possible researcher and personal bias. Five studies used a substantial level of reflexivity (Bergman et al. 2016; Brown et al. 2007; Clare 2002; Daniels et al. 2007; Paun 2003). Future studies should include a higher level of reflexivity. In my study I devoted a considerable amount of time to engaging in reflexivity (see Chapter 8).

Five studies were informed by a grounded theory approach (Beard et al. 2012; Botsford et al. 2012; Brown et al. 2007; Hellström et al. 2007; Jansson et al. 2001; Walters et al. 2010). Two studies used a feminist approach (Eriksson et al. 2013; Paun 2003), four studies used phenomenology (Bergman et al. 2016; Clare 2002; Paun 2003; Sinclair et al. 2018), one study used a naturalistic inquiry (Shim et al. 2013) and two studies used a qualitative constant comparative analysis (Vikström et al. 2005; Vikström et al. 2008). The other six studies did not specify their epistemological position. Although there is some variation in the epistemological position of the studies or they have not been discussed at all, it is clear that most of the studies have an explorative nature. We may have to ask ourselves if other epistemological positions that fit with qualitative methods would be useful to give us a deeper insight into areas that are explored in these studies.

Only two studies had a longitudinal character (Botsford et al. 2012; Hellström et al. 2007). In my study I conducted longitudinal research for over 6 months. This has the potential to give a better insight into the progressive nature of dementia and its influence on the relationship of the couple and the care giving and living experience. Additionally, there is a need for research that explores some of the contradictions shown in these studies. What is the influence of gender and ethnicity on the experience of caring and living with dementia? What are other factors that might influence the caring and living experience?

Although there was some variation in the age, gender and ethnicity of the participants, most studies stated that they included primarily middle-class couples of Caucasian backgrounds. More variation in the studies might give us a better understanding of other factors that influence the experience of caring and living with

dementia. None of the studies focussed on the influence of socio-economic position on this experience.

Most of the studies took place in the Sweden (Bergman et al. 2016; Eriksson et al. 2013; Hellström et al. 2007; Jansson et al. 2001; Vikström et al. 2005; Vikström et al., 2008), the UK (Botsford et al. 2012; Boyle 2013, 2014; Clare 2002; Walters et al. 2010), and the USA (Beard et al. 2012; Brown et al. 2007; Daniels et al. 2007; Paun 2003; Shim et al. 2013). One study took place in Australia (Sinclair et al. 2018) And only one study looked at the caring experience in multiple EU countries (Murray et al. 1999).

Finally, a major omission in the current research is that none of the studies included a focus on co-morbidities, although we know that people with dementia also develop co-existing health conditions that influence the wellbeing of both spouses. Future research into the influence of co-morbidities on the lived experience of people with dementia and co-morbidities would create a better understanding. In my study I set out to examine the influence of co-existing influence of co-existing health conditions on the lived experience for the couple.

There are multiple gaps in understanding and research methods and approaches used that can be filled. A PhD research project is too small to work on all of them. In this thesis I will focus on contributing knowledge on the role of the influence of co-morbidities on the lived experience of spouses of whom one has dementia and the partner is the primary carer. Furthermore, I provide a holistic and explanatory research approach that is used in a longitudinal study based on interpretative ethnography using a variety of data collection methods: informal interviews, semi-structured interviews, participant observation, life history interviews, photo diaries and photo elicitation interviews. In this study both the caring spouse and the person with dementia are participants. And there is variation in the socio-economic position, religion, cultural backgrounds, age and gender of these couples. I will further elaborate on my study design and how it contributes to the spouse care discourse within dementia care in Chapter 3.

2.2.10 Implications for Practice

Not only do most studies set out to explore or describe the care experience, but most of them also discuss implications for practice that stem from their studies. Only two studies do not provide implications for practice (Beard et al. 2012; Murray et al.

1999); the other studies offer diverse implications.

One study advises health care professionals to acknowledge the uniqueness of the couple and the individual, acknowledging ethnicity, the relationship dynamic and gender. Health care professionals should seek insight into the couple's preference for care based on their cultural background and existing family relationships in order to offer them the right support (Botsford et al. 2012). Besides, they should be aware of the diverse ways people from different cultural backgrounds cope with emotions like grief and what role spirituality plays in their coping process (Paun 2003). Not only should healthcare workers increase their awareness of cultural differences in shaping the experience of illness and caring but in general the awareness of dementia has to be created in different ethnic communities to enable timely diagnosis and access to support (Botsford et al. 2012).

Most articles argue that healthcare professionals should acknowledge the uniqueness of spouse carers and their individual needs relating to social contacts and support, the need to share their experience and emotions, the importance of enabling them to keep doing activities they enjoy, helping to them to feel useful, offering access to the right information, helping them to develop the right coping strategies and helping them to maintain a sense of self and identity (Clare 2002).

According to some studies, healthcare professionals should be aware of the couples' perception of their relationship and of the illness, taking into account both individuals' views and acknowledging the uniqueness of each couple's story (Daniels et al. 2007; Vikström et al. 2008).

Interventions for carers should be focussed on creating a connection between the spouses and sustain continuity by creating a favourable environment of care (Walters et al. 2010). Health care professionals should support couples in redefining their relationship, sustaining 'couplehood' (Hellström et al. 2007) and assisting them in working together (Vikström et al. 2005). Also, health care professionals should acknowledge the individual coping strategies of spouse carers and provide them with the right support during the progression of the disease. Protecting the health of the spouse carer by preventing them from being overburdened should be an important goal (Jansson et al. 2001).

Furthermore, some studies suggest that professionals need to be aware of the dynamics within a couple's relationship in order to support them in decision making, for example enabling both spouses to take part in this process (Boyle

2013;Sinclair et al. 2018). Healthcare professionals should acknowledge the influence of gender identity on general expectations and on the perceptions in everyday life about female carers in informal care settings (Eriksson et al. 2013). Health and care organisations need to be considerate of the influence of gender on the care experience when they provide advice and training (Botsford et al. 2012; Boyle 2014).

Besides the need for acknowledgement of the uniqueness of every caring situation and tailored support, some studies also suggest implications for healthcare professionals to change their professional relationship with the couples and rethink their own position as, for example, a nurse. Health care professionals should interact with couples by acknowledging them as persons, focussing on their experiences and being aware of their own being in the world and offering a professional-friendship relation (Bergman et al. 2016). This recommendation is questionable, as a professional-friendship relation might also have negative implications for the role and wellbeing of the healthcare professional.

According to Shim et al. (2013) health care professionals should reflect on their own role as a carer and could learn from informal carers by consciously adapting a certain attitude towards the caring that helps them to give meaning to their jobs, experience personal fulfilment and maintain a work/life balance.

2.2.11 Discussion

The major topics of all studies are closely connected: all of them focus on the relationship of the couple, the identity of both individuals and how both individuals make sense of changes in the relationship as part of the lived experience of dementia. Giving meaning to those experiences is just another perspective on the lived experience.

Although the studies are related, some contradictions are shown. Does someone's gender influence the experience of individuals and couples (Boyle 2013, 2014; Brown et al. 2007; Eriksson et al. 2013; Paun 2003) or do female and male spouse carers have similar experiences, as Murray et al. (1999) suggest? Does the ethnic background of spouse carers influence their experience of caring (Botsford et al. 2012; Paun 2003) or not (Murray et al. 1999)?

I would like to suggest that there is a need for studies that explore the role of gender and ethnicity by being critical about how experiences can also be created or

informed by other characteristics. Also, studies would benefit by including both female and male carers in the study so that a comparison may be made within the study. An identity approach could offer us a perspective that includes the plurality of people's identities based on these characteristics. In this study I will provide an identity perspective that could be further developed to focus on studying the influence of these characteristics on the lived experience in future research.

Themes that have come up in multiple studies are the redefinition process of the relationship, the different phases couples might go through and the importance of continuity in this process. In this thesis I will provide an identity perspective that gives us a better understanding of this redefinition process and shows the complexity and contextuality of this process.

Subthemes connected to this redefinition process that are being discussed are the continuity and disruption in the relationship, the change in role patterns and the identity of the individuals in the relationship and the way they give meaning to their role and identity. These subthemes and their internal relationship could be further researched to show their complexity and their influence on the daily lived experience.

2.2.12 Conclusion

Overall there is a need for explanatory studies. The explorative studies have identified processes and factors that may influence the daily lives of the couples, but they do not offer a detailed understanding of these factors and processes and their variation and contextualisation in different situations. There is a need for studies that adopt holistic perspectives that take into consideration how different factors like co-existing health conditions, gender, socio-economic position, ethnicity and cultural background influence the lived experience of couples of whom one has dementia. Using a holistic perspective enables us to be more critical in ascribing certain experiences to only one of these factors, creating a more detailed picture including a description of the possible co-influence of the factors on each other, which will eventually lead to a deeper understanding.

The first step to accomplishing this is to develop a holistic research approach that allows for such a holistic perspective. One way to do so is to adopt a theoretical framework and methodology that takes into account this holistic perspective. In this study I have developed a holistic approach and show how it provides us a better

understanding of the daily life experience of spouses with dementia and co-morbidities in the community by creating a better understanding of multiple aspects of this experience. In this thesis I will discuss some of these aspects.

In Chapter 4 I will discuss how illness creates disruption in daily life and how the couples try to create continuity. In Chapter 5 I will discuss how stigma influences the daily life experience of couples by playing a big role in identity negotiation. In Chapter 6 I will discuss how identity negotiation is an important part of the process of redefining the couple's relationship. And in Chapter 7 I will discuss how the daily life experience and the identity negotiation and relationship redefinition processes are situated in social networks and the community. Because co-morbidities are an important topic in this study but have been absent from the spouse care literature on lived experience so far, I will provide a synthesis of some of the existing literature on dementia, co-morbidities and care.

2.3 Synthesis on Dementia, Co-morbidities and the Body

2.3.1 Introduction

The prevalence of co-morbidities is high among people living with dementia (Doraiswamy et al. 2002; Scrutton and Urzi Brancati 2016). Some researchers even suggest that the prevalence is higher than expressed in the formal numbers of diagnosis because people with dementia are often underdiagnosed. Symptoms of co-morbidities are difficult to recognise in people with dementia, especially since they may have difficulty communicating these (Bauer et al. 2014). Dementia seems to act as a barrier to accessing care for co-morbidities (Bunn et al. 2017). Little research has been done on this barrier, but the existing literature suggests there is a need for better communication, longer medical appointments and medical advice that takes into consideration the co-morbidities of people with dementia (Bunn et al. 2014; Bunn et al. 2015; Bunn et al. 2017).

There is also a lack of research into the experience of living with dementia and co-morbidities (Bunn et al. 2014). This has been illustrated by the lack of such studies in the systematic synthesis I presented above. I will now give an impression of the current knowledge on dementia and co-morbidities in the context of the lived experience.

2.3.2 Dementia, Co-morbidities and the Lived Experience

Seven out of ten people with dementia have also developed another health condition. The most common co-morbidities are high blood pressure [41 per cent], depression [32 per cent], heart disease [27 per cent], a stroke or mini stroke [18 per cent] and diabetes [13 per cent]. Sometimes these co-morbidities are directly related to the dementia; high blood pressure and diabetes can increase the risk of developing dementia and dementia can increase the risk of having a stroke. Other health conditions may develop coincidentally (APPG 2016).

Scrutton and Brancati (2016) show that co-morbidities in combination with dementia often make the self-management of the health conditions difficult for both partners. The carer has to take over self-management and has to do more tasks and take on more responsibilities as the caring burden increases. Managing the health conditions in combination with the other dimensions of caring and the emotional impact of the changes caused by the onset of the health conditions can be demanding and difficult. Sometimes, with the help of the right interventions, the couple can share the responsibility of managing the health conditions (Mountain and Craig 2012; Mountain 2016). But eventually the carer will have to take on all aspects of the management of the health conditions of the partner, such as the management of medication as shown in the study of Jansson et al. (2001).

Whether this practical care and the management of the health conditions is difficult and creates a caring burden will depend on the health conditions, symptoms and abilities of the person who cares and the person being cared for. Newbronner et al. (2013), for example, note that caring becomes more difficult when the person cared for becomes immobile, loses the ability to communicate or develops other impairments and co-morbidities. And Feil et al. (2012) give the example that when someone has dementia it becomes harder to manage diabetes as they might forget when to eat.

The combination of dementia and other health conditions often creates frailty, a high risk of infection, injuries and/or the development of breathing and eating problems (Zarit and Zarit 2014). Mountain and Craig (2012) note that most couples find it hard to keep a daily routine, let alone manage the multiple health conditions. Newbronner et al. (2013) also speak about the complexity of caring in the case of co-morbidities. Many carers indicate that they need more information on the different health conditions in order to be able to care for their relative (Georges et al. 2008).

Because of the complexity of the interplay of these health conditions and their influence on daily life, the care becomes intensive, complex and time consuming and could contribute to a care burden. Some carers spend up to 14 hours a day caring for their loved one (Butcher et al. 2001; Georges et al. 2008).

The complex and intensive caring situation influences the quality of life of both the carer and the cared for (Connell et al. 2001; Martín-García et al. 2013). Living with dementia and co-morbidities is likely to result in a faster decline in health, more unplanned hospital admissions and an earlier move into a care home. It is important to improve the self-management of the co-morbidities by offering the right support to improve people's quality of life and decrease the negative effects mentioned before. To improve the self-management of the co-morbidities and health care in the home, it is important that we gain a better understanding of the daily life of people with dementia and co-morbidity and their spouse carers (Scrutton and Urzi Brancati 2016).

2.3.3 Discussion and Conclusion

Many people with dementia also have or will develop co-morbidities. These co-morbidities will complicate the care; self-management will become more difficult and caring tasks like medicine management will become more complex. Furthermore, the person with dementia becomes more frail. As a result, care partners need to spend more time caring, which increases the burden of care, which can affect the wellbeing of both spouses. There is a need for interventions that can help couples to self-manage their conditions. Before effective interventions can be developed we need to gain a better understanding of how co-morbidities influence the daily life experience of couples of whom one has dementia and co-morbidities and the partner is the primary carer.

2.4 Summary

Couples in the community who live with dementia and co-morbidities experience both disruption and continuity in their daily lives and their relationship. These are mainly described as changes with which they have to cope both practically and in an emotionally meaningful way. While coping with these changes so as to create continuity, roles and identities change and shift. How people cope with these

changes depends among other things on the way they give meaning to these changes by relying on past experiences and the way they framed past changes. Some couples have ascribed them to the ageing process or as part of the challenges that are expected to be part of a marriage. Although disruption, continuity and the processes of coping have been identified in current studies, there is a lack of explanatory work on these concepts and processes.

In the next chapter I will introduce my research design, including a discussion of Bourdieu's theory of practice which allows for this holistic explanatory approach.

Chapter 3

A Holistic & Explanatory Approach:

Study Design, Theory, Methodology, Methods and Ethics

3.1 Introduction

In this chapter the research approach used in this project will be discussed; the research design and its contextualisation in methodology, theory and ethics will be presented. First, I will provide a more elaborate discussion of Bourdieu's theory of practice, the concept of the body, and the methodology used in the project. Afterwards I will present the research questions, aims and objectives, next I will reflect on the validity and rigour of the design, then discuss the data collection methods, describe the sample and discuss the data analysis process. Finally, I will reflect on the ethical implications of the research design for the researcher and participants.

3.2 Theory and Methodology

The theoretical approach I used in my study was the dialectic relationship as described in *Theory of Practice* by Bourdieu. According to (Bourdieu 1977; Bourdieu 1990) the way we live our lives and make sense of our world is the outcome of a dialectic relationship between our habitus, common sense, body and environment/ field. The habitus consists of our ethos, of the values and ideas which we adopt as part of our upbringing and past experiences: all the things we have experienced so far. The habitus changes over time as we will create new experiences, but within the habitus there is a dominant position for the early experiences in life.

The common sense or 'social habitus' consists of norms, values, ideas and experiences which are shared by the members of a group. It develops when the habitus of individual group members synchronise with each other and creates a shared cultural framework reproduced by members of the group. The cultural framework defines acceptable and favourable behaviour for its members (Mauss 1935; Bourdieu 1977). Bourdieu expands Marcel Mauss's (1935) concept of 'social habitus' by explaining how someone gains a certain 'social habitus' based on class identity, he refers to the social habitus with the concept common sense (Bourdieu

1984; Bourdieu 1998). Bourdieu describes how capital ownership and common sense create a distinct ‘lifestyle’ which will foster a group/class identity. Within the group there will be some variation in lifestyle and experiences but overall there is a group identity. Both the habitus and the common sense are dynamic; they will influence each other and change over time; members of the group have new experiences, members may join or leave the group and the field may change (Bourdieu 1977; Bourdieu 1990).

The environment can be defined as a field existing comprising both the physical environment and the structures we are part of, although the concept of the physical environment has been underdeveloped in his theory (Atkinson 2016: 16). The habitus and the common sense both let people design their own environment and help them to make sense of it, for example in the choice of furniture in the homes of members of different classes (Bourdieu 1984). But the environment also influences the habitus and common sense as it is part of experiences. An example of this is how we create taken-for-granted rules about how to behave in different rooms of a house (Bourdieu 1977; Bourdieu 1990).

The body is the embodiment of the dialectic relationship: the way it behaves and looks is influenced by the habitus, common sense and the environment/field in which it finds itself. The embodiment is the connection between objectivity and subjectivity presented in practice (Lock 1993). This embodiment develops with the field where different types of objectivity and subjectivity interact, namely, the first order objectivity, which includes the distributions of capital, including economic cultural capital, goods and resources; cultural capital, which gives meaning; and social capital, the interaction between people. The second order of objectivity consists of the classification systems that give meaning to function in their bodily and mental presentations. These classification systems give symbolic meaning to an actor’s actions, thoughts, feelings and judgements (Wacquant 1992).

According to Bourdieu these structures are internalised by actors and result in the actor’s subjective dispositions in the field. The objective structures are internalised in the subjective dispositions; to understand the objective structures we need to research the subjective dispositions (Wacquant 1992).

This process of embodiment is semi-subconscious; Bourdieu positions the habitus between the views that action is mechanical or based on rationality:

Social agents are endowed with habitus, inscribed in their bodies by past experiences. These systems of schemes of perception, appreciation and action enable them to perform acts of practical knowledge, based on the identification and recognition of conditional, conventional stimuli to which they are predisposed to react; and, without any explicit definition of ends or rational calculation of means to generate appropriate and endlessly renewed strategies, but within the limits of the structural constrains of which they are the product and which define them (Bourdieu 2000: 138).

The way that agents interact with the field and each other can be compared to playing a game. The rules of the game are the structures and there is competition between the different players to compete for certain dispositions:

We can picture each player as having in front of her a pile of tokens of different colours, each colour corresponding to a given species of capital she holds, so that her relative force in the game, her position in the space of play, and also her strategic orientation towards the game, what we call in French her “game”, the moves that she makes more or less risky or cautious, subversive or conservative depend both on the total number of tokens and on the composition of the piles of tokens she retains, that is, on the volume and structure of her capital at the moment under consideration and the game chances. Huygens spoke of lusiones, again from ludus, to designate objective probabilities, they guarantee him, but also of the evolution over time of the volume and structure of this capital, that is, of his social trajectory and the dispositions, habitus, constituted in the prolonged relation to a definite distribution of objective chances (Bourdieu and Wacquant 1992a: 99).

Bourdieu’s theory will be helpful for exploring the embodiment of the objectivity and subjectivity identifying objective structures and power relations within fields. In this study the field will be that of the family, especially the relationship of the couple. So far Bourdieu’s theory has not often been used on the micro level of the family.

His theory is mostly known as a macro theory in which he looks at individual behaviour within the context of intergroup comparison, for example in his works Distinction (1983) and The Weight of the World (2000). What his concepts of capital and doxa mean in a specific context is based upon dominant norms concerning

these concepts in specific groups, often socio-economic classes. After he draws this macro understanding he positions individuals and their behaviour within this context, their dispositions. Doing so he can draw conclusions on the position of individuals within groups and fields, and on differences between groups and fields. When this macro level analysis has not been made it is impossible to reflect on the disposition of individuals in group or macro field context. However, this does not mean that his theory cannot be a useful lens to solely look at the micro level.

Bourdieu has used his theory on a micro level in the past, during his fieldwork in Algeria. He showed that the family can work as a distinctive field with its own doxa, struggles and power relationships (Atkinson 2016). Still, his theory has been critiqued for not being able to clarify the individuals' experience in those fields and take into account intersectionality and the role of social networks. Also, he has not made clear how an individual can be part of multiple fields and how these may interact (Atkinson 2016).

I am aware of this critique and the complexity of how the fields work in his theory; this study is too short to both develop a new holistic perspective to look at spousal care and engage with his concept of field and its limitations. I decided to consider only the dialectic relationship of his theory and to define the concept environment/field as physical environment. This means that I will not reflect on the influence of the disposition of the couples in the field and how this has been informed by their cultural, social and economic capital. In some vignettes these types of capital might be mentioned, but they are not part of the main discussion or of what the perspective is trying to illustrate.

In this dissertation I will show how Bourdieu's *Theory of Practice* could provide a better understanding of the micro level, in this case the daily life experience of the couples in this study. Bourdieu's dialectic relationship in itself can offer us valuable insights and understanding on a microlevel even when the macrolevel has not been elaborated on. His concepts of habitus and embodiment have been proven to be useful concepts on their own to analyse behaviour and identity of people with dementia as shown by Kontos (2004;2005;2006). I would argue that the other concepts from his dialectic relationship, common sense and environment, can also be valuable in this respect and strengthen our understanding of the microlevel. I will further elaborate on this in Chapter 6.

Nevertheless, I do acknowledge that a further development of the perspective

which I present to you in this dissertation through the development of a conceptualisation of the field that fits with understanding the daily life experience of the couple would be valuable and could be a project for future research. It would give us an opportunity to include an analysis of these types of capital on the lived experience of the couples, which could help to better understand the individual experience connected to socio-economic position, cultural background and social networks.

Even though I am only using the environment/field as a physical environment in this study, I did take into consideration the critique on Bourdieu's theory as mentioned before: that it fails to clarify the individual's experience, that it fails to take into account how people engage in different fields, that it does not pay enough attention to intersectionality and that it does not explain the role of social networks well enough. To counter these limitations, I decided to use Bourdieu's dialectic relationship in combination with identity theory as described by Burke and Stetts (2009). Identity theory does acknowledge that people interact in multiple contexts daily and that how they behave and who they are is context dependent. Identity theory also focusses on the individual and acknowledges the plural identities someone holds. Thus, it can help to understand the individual experience, intersectionality, and how one behaves within social networks. I will explain this in more detail in Chapter 6.

Furthermore, I draw upon an interpretative ethnographic approach to understand the experience of the individual and couple from their perspective. This approach looks at a case as a whole, acknowledging the importance of the personal experience explaining its temporality and its situationally, being mindful of history, social position and environment to analyse the micro level (Boeije et al. 2009). To be able to understand the daily life of people with dementia and co-morbidities and their spouses better I decided to include a focus on the concept of the body. I will now explain further what the importance of this concept is and which definition I applied. I will end the discussion with how this concept fits within the dialectic relationship of Bourdieu.

3.3 The Body and Social Theory

The co-morbidities have an effect not only on the physical functioning of the body and processes within the body but also on people's lives apart from that physical functioning of their bodies and the practical dimensions of care. When focussing on the body using a social theory perspective, we have to acknowledge that the body is also a social construct. We could view the body as carrying cultural symbolism and meaning. The body can be identified as a highly symbolic cultural and political space. Bodies are social, political, empirical, subjective, objective, discursive and narrative entities, the interpretation and experiences of which are grounded in history, theory and experience (Lock and Farquhar 2007). Different parts of our body and different functions of our body will have a different meaning. This meaning is dynamic; it changes over time and may vary in different spaces (Turner 1996; Synnott 2003).

The body of literature on the body as a social construct and its role and symbolism in society is extensive. It is a well-established discourse in many social science traditions like anthropology. I would not be able to present the whole discourse in this thesis, and so, being aware of the limited time and space I have chosen to focus on only part of the discourse. I would like to focus on the body as used in Bourdieu's theory of practice, drawing upon phenomenology and structuralism and how his concept fits within the discourse on the body in the anthropological tradition.

3.3.1 Anthropology and the Body

The body is the concept in this study that brings together the natural and the social, the objective and the subjective. Because of this dualism it has been a long-studied concept within philosophy and human science traditions including anthropology. After Descartes introduced body–mind dualism, ontological and epistemological perspectives changed; gradually social science would view bodies as more than natural objects. Bodies have been studied as symbols, as representations of social order and society, and as lived experiences creating an anthropology of embodiment. One epistemology which has been influential in the development of the anthropology of embodiment, especially the embodiment of the lived experience, is phenomenology (Lock and Farquhar 2007).

The way we perceive objects and phenomena in the world is based on the relationship we have towards them, and the meaning we give to them is based on how we have been taught to see them. The being of something is situated in time and place, and as the relationship and acculturation change over time its place will change, as will its being in itself. The main ontological position of phenomenology is that we cannot see people, the world, phenomena and subjects as separate from each other or existing independently. Everything in the world comes into existence because of its relationship to each other thing; the system in which these relationships take place is our 'world'. It is impossible to understand something when not taking into account the relationships in which it comes into being (Heidegger 1926).

Merleau-Ponty (1962) and, later on, Buytendijk (1965) draw upon phenomenology to define the body as both objective and subjective. Buytendijk (1965) speaks of an ambiguity between being a body as part of the self and the sense of having a body as an object, a system of organs. All bodies go through the same cycles of biological processes such as sleeping, waking up, ageing and dying. But how our social practices are played out is determined not in a biologically informed way but in a socially acquired manner (Turner 1996; Vandebroeck 2017).

The body is part of an open dialect relationship within the world and the people it interacts with, grounded in its cultural and social ties. This dialectic relationship is not deterministic but creates a freedom for creative behaviour next to normative behaviour. The body will adapt itself to the situation it finds itself in according to its dialectic relationship of being in the world. People behave in a taken-for-granted subconscious manner but still experience it (Buytendijk 1965).

The place of the body in phenomenology is merely the place of an internal dialectic relationship which creates semi-subconscious behaviour. Bourdieu takes this theory forwards and explained how the empirical body is also socially constructed by history and structures in society adding an external role of the body to the dialectic relationship; the body represents someone's disposition in the field of practice. His theory still inspires social scientists as it presents a framework for analysing the social construction of embodiment (Lock and Farquhar 2007).

3.3.2 Bourdieu and the Body

Bourdieu critiqued the ideas of identity and the body in Lévi-Strauss's structuralism (Scheper-Hughes and Lock 1987; Lock and Farquhar 2007). According to his structuralism individuals and objects are essentially and solely a function of their disposition in society; their identity is based on group membership and is produced by social and cultural forces, deep structures. Individuals are themselves an expression of culture and society (Fay 1996). Behaviour would be based on deep structures, and motivations for behaviour are assumed to be subconscious (Barrett 2009).

Bourdieu argues that people's dispositions are not that static and are created in an interplay with other factors. To theorise this, he draws upon the dialectic relationship within phenomenology: people, the world, phenomenon and subjects cannot be viewed separate from each other and exist independently. Everything in the world comes into existence because of its relationship to each other thing; the system in which these relationships take place is our 'world' (Heidegger 1926). The body acts upon this interrelationship of being the world subconsciously by 'motor response' (Merleau-Ponty 1962).

Bourdieu both critiques and brings these two approaches together, drawing upon Marcel Mauss's idea of the body as vehicle of expression of a cultural framework in habits (Mauss 1935). Bourdieu (1977; 1990) says that people's group identity is the product of disposition, but this disposition is not solely produced by deep structures but by social, cultural and economic capital in which social structures are embedded and the dialectic relationship between the habitus, environment, body and common sense established within a field. He introduces the body as the concept in which this process of disposition is expressed in the body and behaviour of an individual (Vandebroeck 2017). In this way he creates an inroad to doing empirical research into the contextuality of somebody's body and behaviour by analysing the internal subjective dialectic relationship as developed in phenomenology and how this relationship is rooted in deep structures (Lock 1993; Lock and Farquhar 2007). Bourdieu's theory is helpful for explaining why people who are situated differently cultivate different tastes and have different life 'projects' and how this is socially patterned, and he explains well how these differences are embodied (Farrugia and Woodman 2015).

The dialectic relationship from Bourdieu's theory of practice could possibly be a tool to understand better the daily life experience of people living with dementia and co-morbidities, taking into account the changes in the body and environment while acknowledging the interplay of social structures and past experiences on this experience. The dialectic relationship of Bourdieu's theory of practice has already been used in the dementia discourse by Kontos (2004; 2005; 2006) as a tool to understand embodied selfhood. She draws a relation between past experiences, identity and the behaviour of people's bodies: in her theory the dementia does not obstruct the body from behaving in a manner that is expected due to the person's past experiences even though they might not be able to remember. The dialectic relationship of Bourdieu's theory provides a holistic approach which would be valuable for pushing the discourse further. Moreover, such an approach is needed, as was indicated by the literature review. The approach offers concepts that combine the body and memory as different but still related entities, which offers a valuable tool to look at the lived experience with dementia as shown by Kontos (2004; 2005; 2006; Kontos and Martin 2013). It acknowledges the memory loss but also shows how identity is sustained in the body despite the memory loss.

However, Kontos explored only one aspect of the dialectic relationship of Bourdieu's theory of practice, the embodiment of the habitus, and did not take into consideration co-morbidities. In this thesis I would like to further explore the usefulness of Bourdieu's concepts of the body and habitus to understand the daily life experience with dementia from a holistic perspective. In Chapter 6 I will discuss how Bourdieu's theory of practice fits within the discourse of dementia care research and especially the discourse on selfhood and how it can offer a theory to contribute to the latest developments in the dementia care discourse.

As explained before, a PhD project is too small to take into account all the different concepts of Bourdieu's theory of practice that would have the potential to provide a deeper understanding of the ambiguities and process identified in the literature synthesis on spouse care. Based on the main themes of the inductive phase of my data analysis I have decided to focus on his concepts of the dialectic relationship to explore how dementia and co-morbidity together influence the couple's experience of disruption and continuity in their relationship and daily life from an identity perspective. Now that I have clarified the methodology and main

theoretical framework, apart from identity theory which I will explain in Chapter 6, I will introduce the research questions, aims and objectives of the project.

3.4 Research Questions, Aim and Objectives

The aim for this project was twofold: to gain an understanding of the daily life experience of co-habiting spouses in the community in England one of whom has dementia and co-morbidities and to provide knowledge to improve services for couples such as these. The main research question was:

How do dementia and co-morbidities influence the daily life experience of co-habiting spouses in the community in England?

As shown in systematic synthesis on spouse care presented in the previous chapter many of the changes in the daily lives of the couples relate to or are triggered by or originate in their relationship and the identity of both partners and their expected role patterns. (Beard et al. 2012; Bergman et al. 2016; Botsford et al. 2012; Boyle 2013; Boyle 2014; Brown et al. 2007; Clare 2002; Daniels et al. 2007; Eriksson et al. 2013; Janssn et al. 2001; Hellström et al. 2007; Paun 2003; Shim et al. 2013; Vikström et al. 2005; Vikström et al. 2008; Walters et al. 2010).
The other research questions focus on these themes.

The research questions were:

How does dementia influence the daily routine, relationship and identity of spouses in the community of whom one has dementia and co-morbidities and the partner is the carer?

How do co-morbidities influence the daily routine, relationship and identity of spouses in the community of whom one has dementia and co-morbidities and the partner is the carer?

The objectives of this study were:

- Conduct a systematic search and review of the spouse-care literature in dementia care.
- Conduct a narrative literature review on the theoretical developments in the dementia care discourse.
- Conduct a narrative literature review on the self-hood discourse within dementia care.
- Develop a theoretical framework and perspective drawing up on Bourdieu's theory practice, identity theory and the results of the spouse care literature review.
- Conduct six months of ethnographic fieldwork, paying weekly visits to five cohabiting couples of whom one has got dementia and co-morbidities and the partner is the carer. This fieldwork includes conducting life history interviews, informal interviews and participant observation with the participants.
- Conduct a photo diary study including photo voice interviews with the participants focused on understanding the daily life activities of the couples.
- Create a data analysis framework based on the theoretical framework and the data collected during the fieldwork.
- Analyse the data using the developed framework.
- Write an ethnographic dissertation which shows the daily life experience of the couples living with dementia and how the developed identity perspective creates a better understanding of these daily life experiences.

3.5 Research Design

The design of the ethnographic research was a multiple-case study/comparative case study at the houses of the five couples, the participants. There are multiple reasons why I decided to use a case study design: it offers an opportunity to look at a phenomenon in its real-life context from a holistic perspective; it is an appropriate method to answer explanatory questions; the design fits well with the use of a prior developed theoretical framework to guide the data collection and data analysis and it uses multiple different data collection methods (Yin 2003). Below is the model of the case study design used. The cross-case report at the end is this thesis.

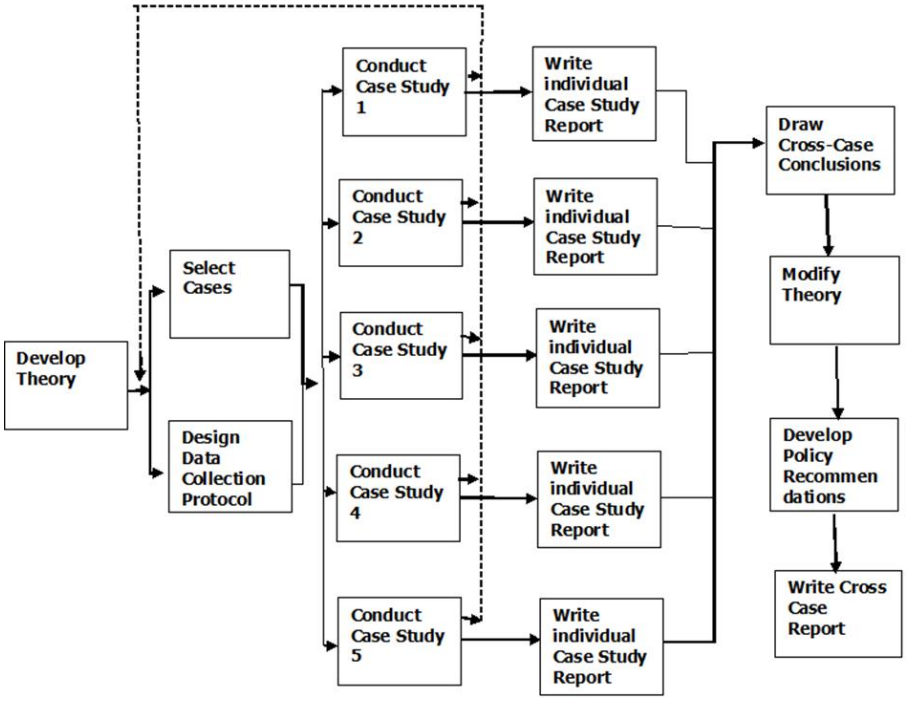

Figure 1: Multiple-case study design (Based on Figure 2.5 Case Study Method) (Yin, 2003, p. 50).

*policy recommendation = implications for care

3.6 Validity, Reflexivity and Triangulation

In this section I will discuss the validity of the study, the reflexivity used, the triangulation used and the saturation. A case study is not generalisable to a bigger population because of the small sample size in which not all the subpopulations of a society are represented (Baarda et al. 2009). However, this multiple-case study is generalisable to theoretical propositions, contributing to theory and expanding its usage. In general, a non-randomised small sample can be a threat to the external validity and its ability to be generalised to theoretical propositions; a clear discussion of theoretical framework, methodological transparency and a sample selection-based theoretical replication, and identical strategies and procedures of data collection and analysis were used in all individual cases (Yin 2003; Hak 2007). These strategies and procedures are outlined this chapter, creating methodological transparency and ensuring the rigour of the study (Boeije 2010).

Besides the external validity I also ensured internal validity and construct validity; I used method triangulation to check the plausibility of the relationships I

identified, the fit of the concepts with the research questions and aim, and to reflect on the limitations and strengths of the data (Yin 2003; Bosch 2012). I further improved the validity, rigour and transparency of the study by the use of reflexivity.

While undertaking qualitative research and more specifically ethnographic work it is important to be aware of how the role and the personal perceptions of the researcher can influence the collected data, as the researcher is her own research tool (Bourdieu and Wacquant 1992b; Hammersley and Atkinson 2007; Plochg and Van Zwieten 2007; Boeije et al. 2009; Boeije 2010; DeWalt and DeWalt 2010; Gilgun 2014). To reflect on my role, personal perceptions, emotions, experiences and opinions, I kept a personal diary throughout the fieldwork period of seven months and I include a reflexive chapter, Chapter 8.

The quality, validity and plausibility of the study were improved by the use of triangulation: theoretical, method and research triangulation (Boeije 2010). Theoretical triangulation is the use of multiple theories and epistemological positions to understand the same phenomena: interpretivist ethnography and Bourdieu's theory of practice. Researcher triangulation controls for researcher's bias; sharing my experiences of the fieldwork with fellow PhD students helped me to reflect on my own assumptions, perceptions and emotions and brought a second pair of eyes in the data analysis phase. Method triangulation was established by the use of multiple methods of data collection: participant observation, informal interviews, life history interviews and photo diaries.

3.6.1 Saturation

Saturation is important in qualitative research as it creates a higher level of validity and rigour of the study. Different understandings of saturation exist, but broadly three points in research have been identified as saturation: there is no new data on the topic to collect, there are no new themes to discover in the data and enough data has been collected to enable replicability of the study (Fusch and Ness 2015).

The third point is not relevant for this study as an ethnographic study does not aim for replicability; the other two points are relevant for this project. The first point of saturation was reached by my reflecting on whether the topics on the topic list had been discussed with all couples and if I was collecting data I had recorded before in my field notes and methodological diary.

The second point was attained by the use of a framework analysis approach which leaves room for both a deductive and inductive approach. In the familiarisation phase, theme saturation is established. The subsection 3.10.2 Data Analysis Method contains an elaborative description of the process of framework analysis.

3.7 Sample

In this section I will discuss what the sample of the study was, the inclusion and exclusion criteria and the recruitment, and I will introduce the participants. The participants in this study were couples of whom one had developed dementia and co-morbidities and their partner was the primary carer, who lived in their own homes in the North of England. It was a small-scale study with only five couples. Each couple is one case, so the study includes five cases. Each case is a holistic case study in itself, all of them embedded in the same society and being service users of the same social health and care system.

I chose my sample size based on a need for diversity in the sample and practical considerations. I aimed for as much variation in couples as possible: variation in the type and stage of dementia, co-morbidity and whether a man or a woman is the caring partner. I also decided that if I wanted to do five house visits a week I had to reserve one day a week for each of them, allowing time to travel to the houses, do the actual visit and write up all the notes, observations and reflections from the visits after returning home. I have used a theory-informed sample (Plochg and Van Zwieten 2007) which is a type of intentional or purposeful sampling (Gilgun 2014).

I aimed for a large variation in the sample informed by the theoretical framework: a variation in socio-economic background, cultural background, type of co-morbidity, gender. A large variation in the sample created the possibility of theoretical generalisability, including couples with different characteristics which predict a different outcome (Yin 2013).

3.7.1 Exclusion and Inclusion Criteria

- The participants need to be a couple, one of whom has developed dementia and co-morbidities and the partner who cares for that person. Couples could only participate if both spouses were able to consent to participate in the study. (Variation in characteristics was possible: married/unmarried, same

sex/opposite sex, different stages of dementia, different types of co-morbidities, different types of dementia.)

- The couple had to be co-habiting and home dwelling in West Yorkshire.
- The couple had to be able to speak English or Dutch, since the researcher speaks those languages.
- The couple could not be involved in similar research or other research that requires much involvement. If they were involved in other research, I asked them if they would have time and energy to also be involved in my project. If this was not the case I would not include them in my study. By having this type of conversation, I protected them from overexposure.

In the end, the sample included two husbands caring for their wives and three wives caring for their husbands. Three couples are of white British background, one couple is of south Asian background and in one couple the husband is Irish and the wife is English. All of them live in West Yorkshire.

The socio-economic position of the couples varied from working class to middle class. There was a variation in the types of co-morbidities of the participants; ranging from mobility problems to chronic illnesses such as diabetes. The age of the participants with dementia ranged from 75 to 88. The age of the carers ranged from 64 to 83.

3.7.2 Recruitment

To recruit I visited fifteen different wellbeing cafés in West Yorkshire. Before I arrived, I contacted the organisers of the wellbeing café to tell them about my project and that I was hoping to meet possible participants at their wellbeing café. Some wellbeing cafés told me they did not want to help me with my project but most of them invited me to come to one of their activities to talk about my project to the people who visit the café.

When I visited the cafés, I brought some flyers and posters with me. I took part in the activity of the café, singing, bingo, dancing, exercise, dominoes, lunch, etc. During the activity I talked to some of the people there to get to know them a little bit and tell them about my project. I also asked the person organising the café if I could have a moment to talk to the whole group about my project. After the talk I

gave people in the café flyers about my project and offered them the opportunity to ask me questions.

While I distributed the flyers I also took the time to talk to people individually, and when someone seemed interested in participating in the project I gave them an information leaflet about the study. At first, I asked people to call me the next week if they were interested. But when this strategy did not prove to be fruitful I decided to ask people who showed interest in taking part in the study for their phone number and called them myself the week after. During this phone call I asked them whether they were still interested in taking part in the study, and if they had any additional questions. If they still showed interest I made an appointment with them to visit them at home to sign the consent form so they could participate in the study.

I found three couples using this recruitment strategy. Four more couples I met at a wellbeing café originally showed interest in participating. I had to reject one couple because the wife's dementia was severe and she was not able to give consent and participate. The other three couples dropped out themselves because of health issues or changes in the home care situation. The health and care situation of those living with dementia and co-morbidities can change quickly and suddenly, so I did expect couples to drop out for these reasons.

The other two couples that I recruited contacted me themselves after a friend or a family member who had attended one of the wellbeing cafés told them about the study and handed them a flyer. These two couples called me to tell me they were interested. I arranged a first visit with each couple, during this visit I gave them an information sheet and introduced my project. A week after the first visit I called them again to see if they wanted to participate in the project. Both couples showed interest in being in the project so I arranged a further visit to sign the consent forms.

3.7.3 Participants[3]

3.7.3.1. Jane and Alan

Jane and Alan have been married for 48 years. They have known each other 49 years. Jane is English and Alan is Irish. They met in a dance hall in the North of England. Both of them are in their seventies; Jane is a bit younger than Alan. They live in a terraced house in a suburb of a major city in North England. They have

[3] Note: All health conditions are described as participants described them to me. Most of them could not remember with which type of dementia they or their partner had been diagnosed.

always lived in the same area but moved house a couple of times. Their Catholic belief is important to them.

They have two children and used to care for foster children. Some family members live locally and some live further away. They also have a lot of friends all over the country and are actively involved in the community. They have a son and a daughter, but they do not seem to have much contact with their son. However, they do talk to their daughter daily. Their daughter and son-in-law live close by and visit them weekly. They provide support, like joining them at important medical appointments and driving them places when needed.

Alan had several jobs during his career, mainly manual work, in factories, as a decorator, and working in a kitchen. Jane used to work at a school as an administrator, tried to start her own bakery/café and used to work in a kitchen. In this last job Jane and Alan worked together.

Both Jane and Alan have multiple health conditions; Jane has back problems, coeliac disease and osteoporosis and is trying to lose weight. Alan has diabetes, dementia, COPD (chronic obstructive pulmonary disease), heart problems, cellulitis in his knees, ulcers on his legs, bad eczema, a hearing problem and mobility problems. Although Jane has multiple health conditions herself she is the main carer for Alan.

Photo 1A Jane & Alan in their living room[4]

[4] Participants approved of publication

3.7.3.2. Diane and John

John and Diane have been married for over thirty years and live together in a semi-detached house in a suburb of a big city in the North of England. John is in his seventies and Diane is in her sixties. They met after they both had been married before. John was in his forties and Diane in her thirties. John has lived in the same semi-detached house since his first marriage and Diane moved in with him after they met. Both of them are retired; John used to be an accountant and Diane used to be a primary school teacher. They have one son who lives locally and visits them weekly. They are also close with their extended family and especially regularly spend time with John's brother, who also has dementia, and his wife.

John likes sports a lot and used to practise multiple sports, of which football was one of his favourites. Together they like to watch football and support one of the major football teams in England. Diane likes music, yoga, working out and walking, but lately she has not had much time for these activities.

Both of them have health issues. Diane has high blood pressure and needs to lose weight. John has mixed dementia, a heart condition, bladder problems (incontinence), dementia, cellulitis and arthritis in his hip and he needs reading glasses. He also told me that he had a kidney removed in his teens. In the past he also had thrombosis in his legs; that is how they found out about the heart problem.

Photo 2A John & Diane ‘Enjoying a coffee after singing group’[5][6]

3.7.3.3. Aaisha and Hamid

Hamid and Aaisha[7] moved to England from Pakistan fifty years ago. Aaisha is in her late seventies and Hamid is in his late eighties. They have always lived in the same city and have lived in the same house for fifty years. It is a semi-detached house on the corner of a row of terraced houses in a neighbourhood close to the city centre in a North English city. They have three sons and two daughters, all of whom live in other cities at least an hour away. Their daily life mostly takes place in the house and the local mosque and community centre. Since Hamid lost his ability to drive they do not have a car anymore and going places can be difficult.

Aaisha used to be homemaker and Hamid used to be a primary school teacher. Hamid has dementia, mobility problems and a hearing problem, and had to have a new pair of knees a couple of years ago. Aaisha wears glasses and also had to have a new pair of knees a couple of years ago. Aaisha cares for Hamid.

3.7.3.4. Bob and Sue

Bob and Sue are both in their eighties and have been married for almost sixty years. They live together in a semi-detached house with a front and back garden in a suburb of a major city in the North of England. They have one son who lives at the other side of the country with his wife and two sons. Their son calls them regularly and they visit their extended family, such as cousins or a sister-in-law, weekly.

Bob drives them around and they enjoy visiting the extended family members. Bob enjoys seeing live music, preferably big band music, and visiting his local pub on Friday evening. Sue enjoys going to bingo nights at a local community centre.

Bob had different jobs throughout his life: he was a tailor, a milkman and an electrician. Sue used to work in an administrative job. Sue has dementia and eye problems while Bob has diabetes. Bob cares for Sue.

[5] Description the couple gave for the picture in their photo diary
[6] Participants approved of publication
[7] No photos are included as the couple requested their pictures be used for analysis only.

Photo 3A Bob & Sue doing the dishes in their kitchen[8]

3.7.3.5. Dan and Mary

Dan and Mary have been married for almost 60 years. They live together in their own home in a small town close to a big city in the North of England. They own a detached house with a garage and front and back garden. They have a son and daughter. Their son lives at the other side of the country with his wife, and their daughter lives in the same town as Dan and Mary with her husband and their two children. Their son calls them every week and their daughter visits at least once a week. They also stay in touch with some extended family, including cousins, and they have a big group of friends they met during church activities with whom they meet regularly. They are Methodist and religion is important to them.

Dan still drives a car and drives them to both appointments and outings. They enjoy drives out. They used to go and have a cup of tea in another town or visit a family member like a cousin, or a friend. They also visit a dementia singing group every week and a wellbeing café every month (dementia support group).

Mary has dementia, diabetes, macular disease, back problems, knee problems and more mobility problems. Dan has a heart condition and lost one of his eyes when he was a child. The doctor also recently told him he was at risk of developing diabetes and he experiences some hearing problems. Dan cares for Mary.

[8] Participants approved of publication

Photo 4A Dan & Mary in their dining room[9]

3.8 Methods

I conducted ethnographic fieldwork. Ethnographic fieldwork is based on the principle of 'being there', spending a long time with the same participants to build rapport over time and joining them on day-to-day activities when possible (DeWalt and DeWalt 2010). This research approach can be used both to create and to test theories (Fife 2005). Therefore, it is a useful method for creating an explanatory research approach based on well-established social theories such as identity theory and the dialectic relationship from Bourdieu's theory of practice.

Ethnographic fieldwork can include multiple types of data collection methods (Fife 2005). In this project I used the following methods: participant observation, informal interviews, life history interviews, the photo diary method and keeping field notes. The data collection took place from February 2017 to mid-August 2017, during which time I visited the participants once a week at a time and on a day that suited them. Either the visit took place in their house or I joined them on an activity that was part of their daily routine outside of the house, starting at their house. The data analysis took place from September 2017 to April 2018. I will reflect further on recruitment in the chapter on entering the field. I will now discuss the methods of data collection individually and afterwards I will explain the process of data analysis and its different phases.

[9] Participants approved of publication

3.9 Methods of Data Collection

3.9.1 Participant Observation

Participant observation is a combination of participation in and observation of some aspects of the daily life of the participants. It is not pure observation, as the researcher will interact with the participants and will not try to minimise or hid his or her attendance in the situation. But it is not full participation either as the researcher is not ‘going native’ or ‘becoming the phenomena’. A certain level of distance is needed to grant reflexivity and enable the researcher to analyse (DeWalt and DeWalt 2010). There are different kinds of participant observation possible, ranging from passive participation to full participation. These different levels of participation are associated with different levels f membership in the community the researcher is doing the research in, from no membership to complete membership (Adler and Adler 1987).

This research project took place at the homes of vulnerable people coping with health care and social needs, so I aimed at a moderate level of participation in combination with a peripheral membership. I liked to be accepted in their house and as a trusted person to speak to but I wanted to avoid having them become reliant on me for additional support. I managed to create this level of involvement but sometimes I had to draw boundaries; one couple said that they would treat me like a daughter. I told them that was very kind of them but I was still only the researcher and could not come around very often. They also asked me if I could sit with the wife for a couple of hours when the husband had to do activities outside of the house. I kindly declined and told them that I did not have time to do so. Instead I told them about organisations and/or charities from which they could access this kind of service. I did not want to accept a fictive kinship relationship as it would imply certain responsibilities and expectations that I could not fulfil (Cassell 2016).

Another reason to safeguard a certain distance between me and the participants was the nature of the research topic; it triggers a lot of emotions. It was important to safeguard the emotional wellbeing of the couple and myself. In an interview I had with one of my participants on the future prospect of her husband having to move into nursing home care, she became very emotional and started crying. The GP had just advised her that it was time for her husband to move into

care, but she said she was not ready for this transition yet. Although I would have liked to give her a hug as we had known each other for over four months at that time I decided not to do so; instead I asked her if she was all right, offered to change the topic of conversation and gave her some time to cope with the emotion.

Before the start of the project I knew that managing these relationships and guarding boundaries would be one of the most difficult parts of the project. I will reflect further on this in Chapter 8 (Adler and Adler 1987; DeWalt and DeWalt 2010). Having worked in dementia care myself and being keen on helping others, I had to reflect on my role as researcher and draw these boundaries although they sometimes went against my intuition.

The participant observation also includes informal interviews and making field notes, which I will explain later, and taking pictures of objects in the house that have a special meaning in the situation or for the participants (DeWalt and DeWalt 2010). I did not take many pictures myself during the fieldwork; most participants did not feel very comfortable with that possibility, and they had all agreed to keep their own photo diary, so I decided that this would be the part of the study of which they were in charge, although guided by some instructions. One couple encouraged me to take pictures of objects in their home that they used to cope with the health conditions; they felt it would improve my study if others could see what adjustments can be made to one's house to help one cope.

I also had to draw other boundaries concerning safety and responsibility. It is difficult to decide when a researcher has to step in when they observe something in the house or care practice that could potentially be harmful to the spouses. I decided to step in when the situation could potentially be harmful and no one else did so. In one case, I was interviewing the spouse carer when the other spouse tried to boil water by putting a kettle on the hob that was not suitable for use on a hob. The spouse did not notice as she was sitting with her back turned to the scene. I warned her and she took the kettle off the hob in time. She also told me that they had had an accident of a little fire in the kitchen before, so she had a switch installed on the hob so her husband could no longer use it when she was not around.

In this situation it was not too difficult to decide that I had to step in. Another situation was more difficult to judge. In one couple, the wife with dementia always took the bus on her own to another city. But lately she often got confused or lost doing so. The husband told me he did not know what to do: whether he should stop

his wife from going out on her own or leave her to it; he did not want to take away her independence. He also told me that he was going to talk about it with a social worker as his son had pushed for that. Since he was going to seek advice from a social worker, who has experience in advising on such situations, I told him I understood both of his considerations and encouraged him to seek advice from the social worker. I decided it was not my place to advise him to either stop his wife from going out on her own or leaving her to it.

3.9.2 Informal Interviews[10]

The topics of the informal interviews were based on a topic list which consisted of themes that came out of the literature reviews, the concepts form the theoretical framework and themes that were captured in the field notes during the fieldwork. The informal interviews were like conversations: sometimes I would ask questions to guide the conversation but there was plenty of room for the participants to include topics they found important (DeWalt and DeWalt 2010). This format enabled participants to take the lead in the interview and influence the choice of topics discussed; when talking about family dynamics one of the couples shared with me their past experience of being foster parents. Although they no longer had contact with their foster son, making the experience not directly relevant for their current family support system, it did present me with a context in which their family dynamics had always encouraged each other to care for others. Having this flexible and open approach to the interviews eventually led to rich data in the context of their current daily life experiences. The interviews were recorded with a voice recorder and transcribed either by me or a transcription company.

It proved to be difficult to do interviews with the person with dementia individually; they were not always able to answer questions by themselves. Especially switching topics and following the flow of a conversation proved to be challenging. The spouses often helped the person with dementia to take part in the conversation by explaining things in a way they understood, referring to something in the past that helped their partner remember or simply answering the question for them and asking their partner to confirm the answer.

[10] The Appendix includes an interview guide and topic list.

3.9.3 Life History

Sharing a story/narrative is an important way for people to confirm their identity, especially when they, specifically people with dementia, have to deal with the loss of abilities, roles and activities that helped them confirm their identity (Kotai-Ewers 2011). Enabling participants to share their life story can help them to confirm their identity and enhance their wellbeing. The process itself of sharing a life history story can be difficult; people will reflect on both joyful and challenging times in their life, possibly upsetting the participant.

In this project I gave all the participants the choice of taking part in the life history interview or not; four carers and three people with dementia took part. One couple dropped out of the study after three months because the husband moved on to a palliative care pathway; they left the study before I was able to do the life history interviews with them. One person with dementia refused to do a life history interview as she was not interested in telling me about her past life. It was challenging to do life history interviews with the people with dementia, and I will reflect on that later in this chapter.

In all of the life history interviews there were moments when participants became a bit emotional because they were asked to talk about a difficult time in their life. I allowed them space to decide for themselves how much they wanted to say about this event. Some of them would only briefly talk about it or even avoid the topic, while others seemed to like spending a lot of time sharing the story. Being flexible as an interviewer helps guide the participant through their story. It is important to acknowledge that it is their story and they will share the facts which they want to share on the topics.

All the participants with dementia in my study found it challenging to do a life history interview. They had difficulty retrieving memories from their long-term memory, putting them in the correct chronological order and reflecting on them. Especially the structured approach I used with pre-formulated questions did not work well when interviewing people with dementia; sometimes a switch from a topic like their past professional life to a question about their religious beliefs proved to be challenging, as they would keep referring to the first topic.

All of the participants in the study had memories from the past which were easy to retrieve and were dominant; when asked anything about the past they would refer to those specific memories. One woman in the study lost her father when she

was about four. Growing up without him influenced many decisions she made over the rest of her life, and when asked about the past she would always talk about the loss of her dad, even when that did not answer the question. I decided that the life history of the people with dementia in this study would consist of those memories that they could still retrieve, whether or not these answered the pre-set life history questions.

This reflection on the use of life history with people with dementia seems to contradict the dominant discourse on reminiscence and dementia in which the long-term memory is assumed to keep functioning quite well for a long time. Schweitzer (2011) stated that reflecting on the past together with people close to them provides a tool to reconnect with each other and empower people to confirm their place in the social world. We do need to acknowledge that reminiscences may not be for everyone, as some people may not be able to remember and others do not like to talk about their past, possibly because it reminds them of the loss of their abilities (Bartlett 2012).

Also, we need to reflect on the possible limitations of reminiscence when people are only able to remember a couple of dominant memories from their past. It might not be possible to or to reconnect with their partners through other memories**.** One woman in my study did not recall being married to her husband; even when her husband tried to reminiscence with her using pictures and telling her about their son she was unable to remember. Not being able to do structured life history interviews with the participants with dementia did not present me with a problem in terms of data collection. On the contrary, it proved to be a valuable datum for which Bourdieu's concepts of habitus and common sense were useful frameworks of analysis. I will elaborate on this in Chapter 6.

3.9.4 Photo Diaries

Being aware that five of my participants had dementia and that some of the more traditional research methods in ethnographic research, like informal interviews, might not be the best ways to ask them about their experiences because the cognitive impairment can make holding a conversation challenging (Shell 2014; Velzke and Baumann 2017), I decided to include a participatory research method in my project.

There is a growing interest in using participatory research methods in dementia care research as there is an awareness that it is important to include

people with dementia in research, as participants or even co-researchers (McKeown et al. 2010; Bartlett 2012; Capstick 2012; Tanner 2012; Shell 2014; Swarbrick et al. 2016).

The photo diary method is an established participatory method that offers participants the ability to collect data themselves, leaves them some freedom about what they should picture and creates a space to reflect on what is captured in the pictures in a photo voice interview. Participants can create their own narrative and reflect on this by picturing it. They gain some control on what data should be collected and thus become co-researchers (McIntyre 2003; Heath and Cleaver 2004; Holliday 2004; Close 2007; Guerra et al. 2013; Snowden 2015).

The photo diary method consisted of two phases: taking the pictures and doing a photo voice interview. All participants in the study were asked to keep an individual photo diary, taking one picture a day showing an object, activity or person that is part of their daily routine for 28 days in a row. They could choose whether to use their own device or a disposable camera provided by me. One couple choice to use their own mobile phone, while the others used a disposable camera.

When participants forgot to take a picture, it did not create a problem; what was important was not that they took all twenty-eight pictures but what they pictured. Still, I asked them about the progress on their photo diary at every weekly visit. The couple that used their mobile phone sent me a picture a day over WhatsApp, and the chosen device allowed me to send a prompt when I had not received a picture yet that day.

Although the diaries were intended to be individual projects, all couples made them shared projects. Some couples produced two separate diaries of one picture a day, while others produced one diary together. Some of them took the asked 28 or 56 pictures, while others took fewer pictures. Some finished in 28 days; others took a lot longer to produce a diary.

The next phase was the photo voice interview; depending on the number of pictures I planned one or several photo voice interviews with the participants. I gave all participants the choice of whether they would have individual or shared photo voice interviews. All couples chose to do the interviews together. The interview questions where guided by the pictures. Examples of these questions are: '*Why is this activity important to you? How often would you do this activity? When did you do this activity? Do you usually do this together? Has the activity changed since the*

onset of the dementia?'

These interviews revealed parts of the daily life routine that were important to the couples but that we had not talked about before. The photos also served as a prompt for memory (Chaplin 2004; Whincup 2004), helping the participants with dementia to talk about the daily life routine. The downside of the pictures as a prompt for memory was that they confronted participants with their lost abilities (Bartlett 2012; Velzke and Baumann 2017).

The photo diary method provided a valuable addition to the other methods as it helped me to collect data on topics I had not collected much data on before, especially daily life routine activities outside of the home. Besides, the method strengthened the interpretative ethnographic approach because participants had a chance to show me part of their daily routine from their perspective.

3.9.5 Field Notes[11]

During the seven months of data collection I made field notes; from the moment that I entered the research field, during recruitment, I started making field notes. These notes were mainly descriptive and include jotted notes of what I observed with detailed description, sketches of objects and spaces, and logs of daily routines (DeWalt and DeWalt 2010; Fontein 2014). I jotted notes on a notepad and digitalised them later that day by extending the jottings into detailed field notes which I dated. None of the participants found the jotting intrusive, distracting or unpleasant; some of them even encouraged me to write more as they felt it was important information that had to be recorded (DeWalt and DeWalt 2010). In addition to the field notes I kept a personal and methodological diary to reflect on both the field notes and research practice.

The field notes are a construct of the researcher but the personal diary can help to obtain reflexivity and grant a level of objectivity. It is important to keep these reflections separate from the field notes themselves (Fontein 2014). I anonymised the field notes and stored both the field notes and diaries on my computer and OneDrive, secured by a password (DeWalt and DeWalt 2010).

[11] For a further elaboration on this I would like to refer to the confidentiality section in my ethics protocol in the Appendix.

3.10 Data Analysis Process

In this section I will give an elaborate overview of the data analysis process, discussing different phases of the analysis. LeCompte and Schensul's (1999) guide on analysing and interpreting ethnographic research served as my guide for working in different stages of data organisation and analysis. First, I will discuss how I organised the data in an index and maps. Secondly, I will discuss the data analysis process and its five different stages: familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation. Thirdly I will discuss my strategies to interpret the data and the creation of case study reports. Finally, I will reflect on the process of creating vignettes and deciding on the scenes to include in the thesis.

3.10.1 Organising the Data

Organising the data was an important first step because of the big data set. In the six months during which I conducted fieldwork with the five couples I collected a substantial amount of data: 287 pieces varying in source (photos, field notes, interview transcripts etc.) and length.

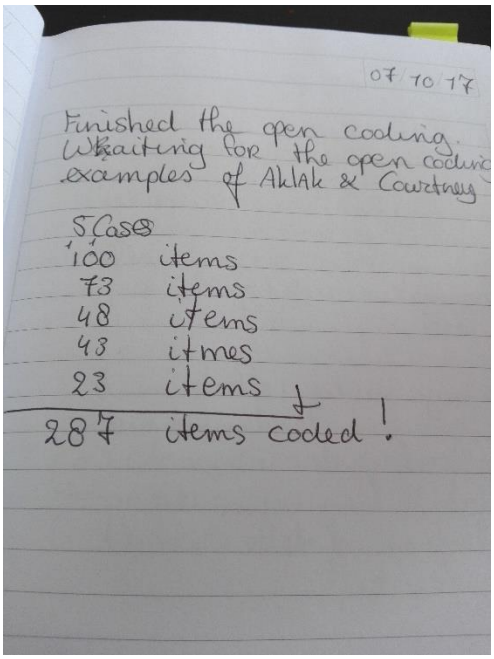

Photo 1B Page from my data analysis notebook counting pieces of data after I finished the first round of analysis for all cases.

I kept a notebook in which I created an index of all the data I collected for each case, kept track of my different rounds of data analysis for each case and wrote down the different stages in which I developed the theoretical framework for data analysis.

First, I indexed all the collected data for each separate case in a table and indicated when I collected which data. This helped me to connected data from the same case that had been collected at the same day. This index also gave me an overview of possible missing personal diary pages. Because the fieldwork had been such an intensive six months in which I sometimes visited two couples on the same day, I did not always manage to write a separate personal diary page next to the field notes.

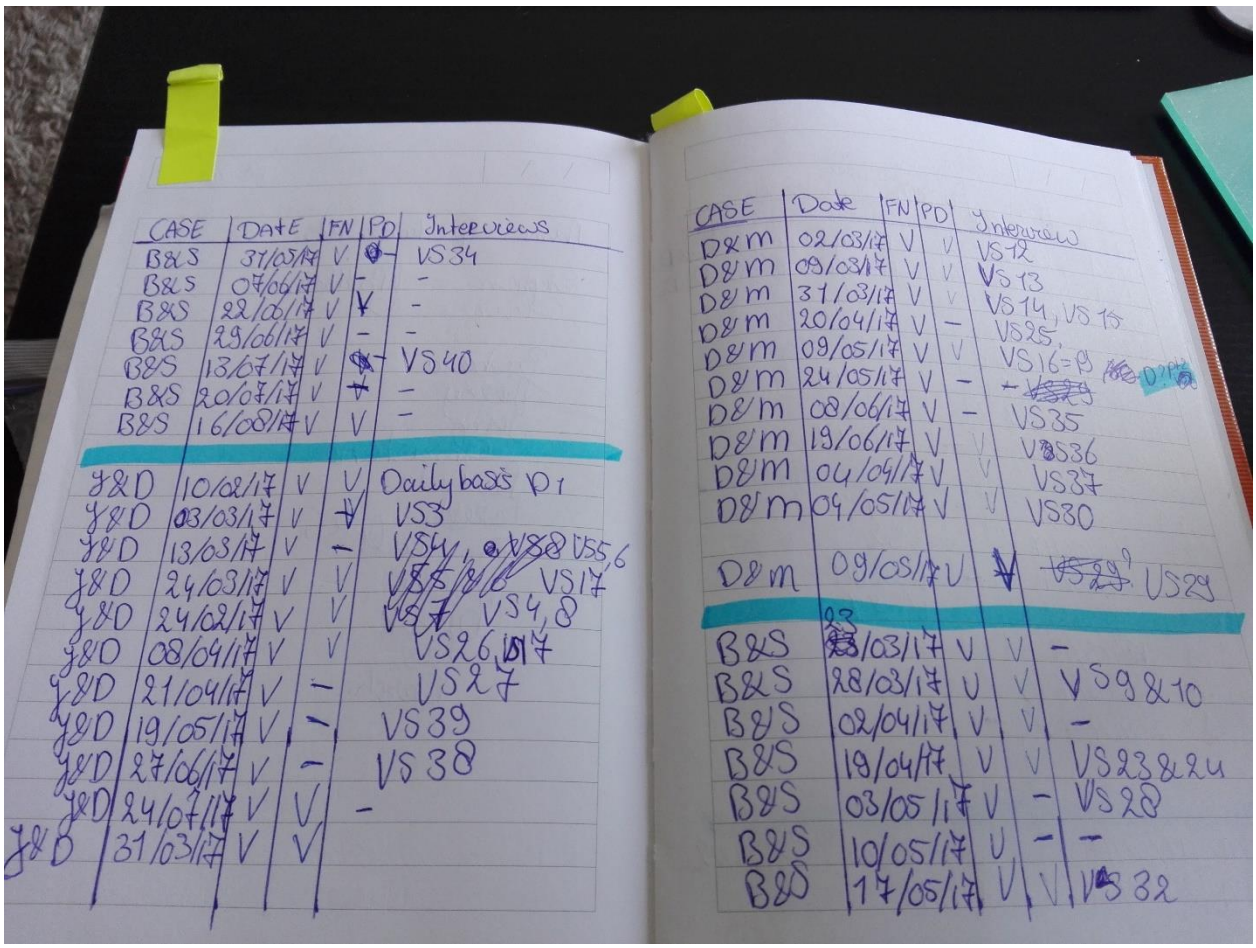

Photo 2B Two pages from the index

Photo 2B shows two pages from the index. Column one, *case*, indicates which case study is referred to, column two indicates the date the data was collected, column

three indicates whether I had field notes for that date and column four indicates whether I wrote a personal diary page on that day (checkmark for yes or dash for no). Finally, column five indicates whether I did an interview that day and under which name (for example VS15) I could find it again in the folder of data of each case.

The photo diary photos were not indexed in this index. It was impossible to know on which day the participants had taken the pictures because most of them used disposable cameras which did not log the date of the picture. However, the pictures were stored for each case in a separate subfolder of the case folder. The photo elicitation interviews were indexed in this index as I knew on which date I conducted these interviews.

Each case was organised in a separate folder with subfolders organised by the type of data they stored as shown in photo 3B below. The index and folder system functioned well together. The index gave me a clear overview of the data I collected and when I collected it, and under which name I could find it in the folders. This made it easier to go back to specific transcripts, field notes or personal diary pages while conducting the data analysis.

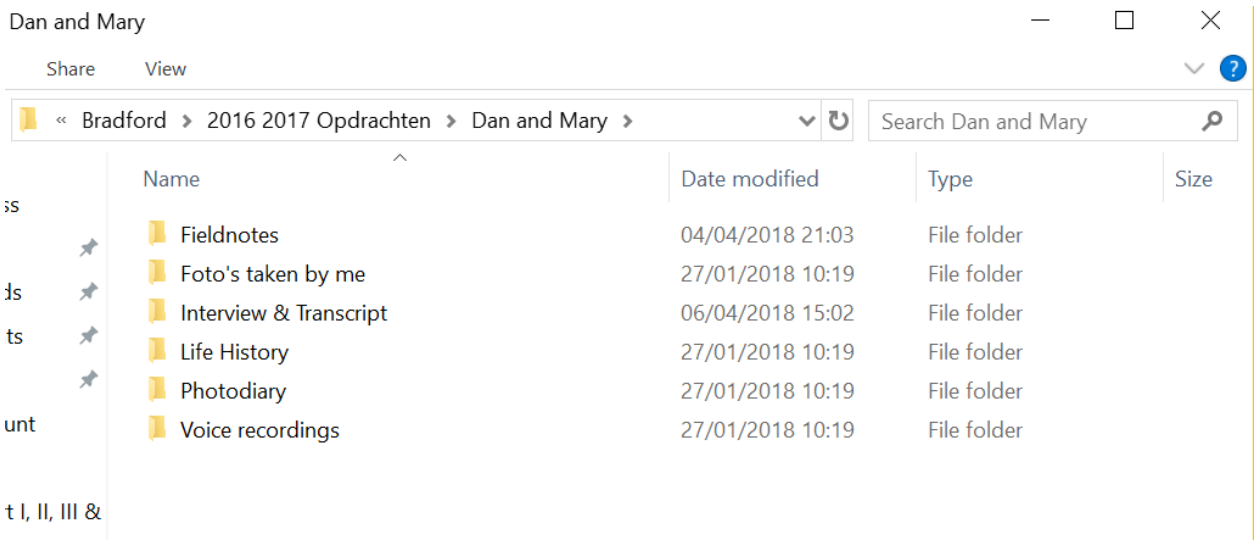

Photo 3B Example of a case storage folder including its subfolders

3.10.2 Data Analysis Method

The method of data analysis I used is framework analysis; it is both inductive and deductive, allowing for the simultaneous usage of an a priori theoretical framework

for analysis and the development of themes out of the data. Furthermore, it enabled me to do a systematic analysis within and across cases by organising the data in clear databases/frameworks which are easy to compare (Ritchie and Spencer 2002).

The method was developed in applied policy research to create transparency in the processes by developing databases to give funding bodies insight into the analysis process; this clarity allowed for multiple researchers to work effectively together on the analysis of data (Ritchie and Spencer 2002). In my data analysis process, I asked two fellow PhD students to code 5 percent of the data, which I also coded, to compare and control for researcher's bias. Its origin in applied policy research also made the method applicable for analysing data with a limited time scale. In framework analysis data there is only one round of data analysis; this fits well with the case study approach that also adopts that principle (Yin 2003). Framework analysis has been used for different kinds of qualitative research. It is mostly used for the analysis of structured or semi-structured interviews but can also be used for analysing data that has been collected with different methods, like an ethnographic study (Ritchie and Spencer 2002; Ward et al. 2013).

The framework analysis process adopts five stages of analysis, namely familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation. I analysed all cases separately but completed every stage for every case around the same time, meaning I that I finished the first phase with every case before moving to the second phase with all cases.

The process started with familiarisation; I immersed myself in the data, listened to some of the interview recordings again, read all the transcripts, field notes and applicable personal diary pages and viewed the pictures from the photo diaries, starting the process of conceptualisation and identifying themes through thematic analysis.

Afterwards I identified a thematic framework for the analysis, using both the themes from the familiarisation phase and the themes and concepts that were part of the theoretical framework and research questions, aims and objectives.

I first made a list of all the themes that related to the spouse care literature and research questions; next I made a list of themes and concepts that related to the theories I planned to use. Afterwards I tried to fuse these themes together and reflected on how different themes were connected and or overlapping. Eventually

these steps led to a standardised data analysis framework that was the fundament for the creation of case-specific frameworks.

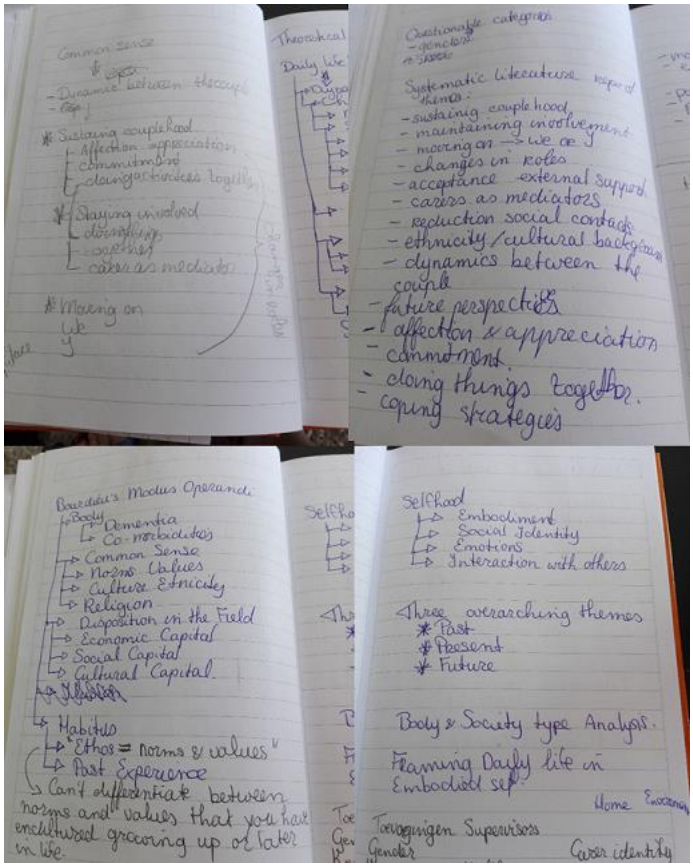

Photo 4B Lists of themes and concepts in data analysis notebook

Photo 4B above shows notes from my data analysis notebook, in which I wrote down possible codes and how they could relate to each other. This is illustrated in the actual basic framework presented in figure 2 on the next page.

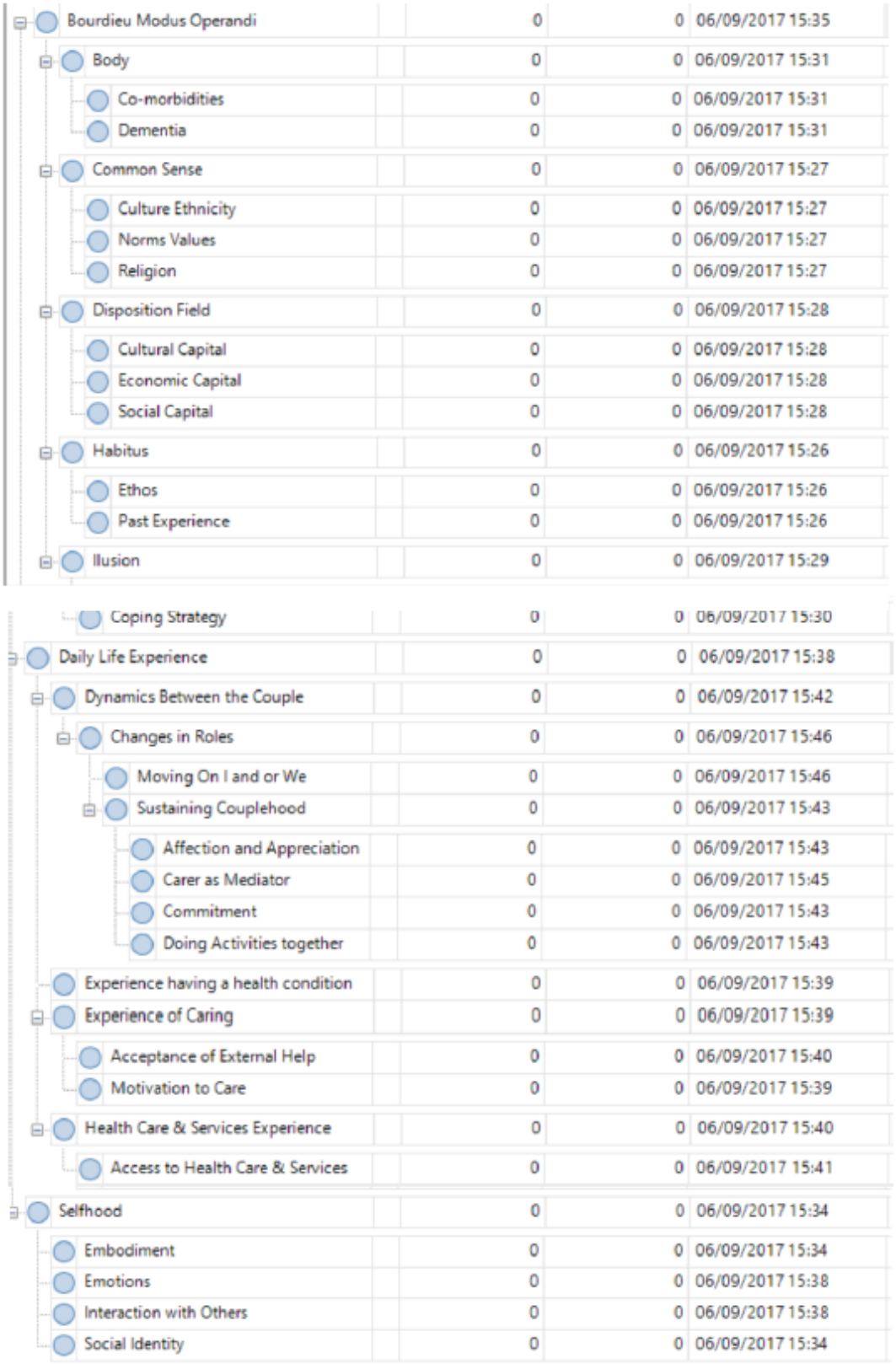

Figure 2 Basic framework for framework analysis[12]

[12] It is worth noting that in a later stage I decided to include gender as a code in all frameworks as well. This is not shown in figure 2 because I included it in all framework-specific frameworks.

Figure 3 below shows an overview of the origin of all codes in the basic framework including gender:

Codes based on Bourdieu's theory of practice	Codes based on the selfhood discourse	Codes based on the systematic synthesis of spouse care & research questions	Codes based on the aims & objectives of the study
○ body ○ common sense ○ cultural capital ○ economic capital ○ social capital ○ habitus ○ ethos ○ past experience ○ illusion ○ cultural background &/or ethnicity ○ norms and values ○ religion	○ embodiment ○ emotions ○ interaction with others ○ social identity	○ daily life experience ○ dynamic between the couple ○ changes in roles ○ moving on 'I' and or 'We' ○ sustaining couplehood ○ affection & appreciation ○ carer as mediator ○ commitment ○ doing activities together ○ experience of having health conditions ○ experience of caring ○ accepting external help ○ motivation to care ○ gender	○ health care & services experience ○ access to health care & services

Figure 3 Origin codes

Even though I developed a basic code framework to be used in every case, the framework of each case looked different because of the case-specific codes that were included. In the familiarisation phase of data analysis in each case, I identified themes that were not yet represented in the basic framework. Appendix 4 includes one example of a case-specific framework.

After creating a case-specific framework for the first case, I asked two fellow PhD students to code some of my data from this case and reflect on whether the data analysis framework represented the themes from the data. They gave feedback on how the data corresponded with the themes and suggested additional themes to be included in the framework.

After developing a framework for each case, I could start with the indexing phase. In this phase I connected the data to the framework by labelling the data according to the themes and at the same time I created a chart using the labels of the index with summaries of the data on each label/theme (Ritchie and Spencer 2002). I created an individual index for each specific case. An example of such an index can be found in Appendix 4. When all indexes were created I wrote individual case study reports which were both descriptive and the first stage of interpretation. I based each report on the index of the case. Appendix 4 also contains an example of a case study report.

3.10.3 Interpretation of the Data and Creation of Vignettes

This phase was followed by the mapping and interpretations of the data in which I used some pattern matching to compare the theory with the data and selected data from each case that challenged the theory, confirmed the theory or for which the theory created a substantially deeper understanding by representing the complexity of the situation. I decided to create short and long vignettes with most of this data. The vignettes I created were either normative depictions or dramas or critical events.

Normative depictions are descriptions of what the researcher considers to be ‘typical’, regular, normal events in the lives of the participants. Dramas and critical events are out-of-the-ordinary events that take the reader’s attention, signify a turning point in the ethnographer’s understanding or seem to be a contradiction to earlier understanding but actually show another level of complexity (LeCompte and Schensul 1999).

Most of the vignettes I created are normative vignettes to give the reader an interpretivist view of the daily life experiences of the couples. There are also a substantial number of critical event vignettes, because these events created a deeper understanding of the couples’ daily life experience and especially the way they experienced and negotiated identity. I already reflected on these events in my field notes and personal diary before data analysis. In combination with the dominant

themes that were identified in the framework analysis phase they have informed my choice for the argument of the thesis and topics of the separate chapters.

Especially the importance of stigma in the daily life experience became clear to me when I thought about some of the critical events in which some of the participants rejected or denied the dementia diagnosis. Finally, there are also a couple of vignettes of dramatic events. I mainly included these vignettes because these types of 'drama' may not happen daily but they are still events that many couples of whom one has dementia and co-morbidities experience, and they illustrate some of the disruptive moments that these couples experience in their daily lives. Figure 4 below presents an overview of all included vignettes and their types.

Normative vignettes	Critical event vignettes	Drama vignettes
○ 'A Typical Friday' Chapter 3 ○ 'Questioning God' Chapter 3 ○ 'Reiki & Reflexology' Chapter 3 ○ 'Routine Medical Appointments' ○ Chapter 3 ○ 'It does not bother me; the development of a 'new' Normal Chapter 3 ○ 'You know, because Alan has good days and bad days, and is somebody who is very confused' Chapter 4 ○ Jane & Alan Chapter 4 ○ Diane & John Chapter 4 ○ Bob & Sue Chapter 4 ○ 'I did not marry him. It is true, I am not joking, no. He does not like me telling you, but we were not married'. Chapter 5 ○ 'It is a slow process but Aaisha waits patiently' Chapter 5 ○ 'The busride' Chapter 6 ○ 'She never needed to go to the hairdresser but I think nowadays she does' Chapter 6 ○ 'And I just think, oh, just be quiet' Chapter 6	○ Opening Vignette Chapter 4 ○ 'Yeah. I never mention that to her. No, no! She will just say; I haven't got that' Chapter 4 ○ 'I never mention she has dementia to her, I just call it memory loss' Chapter 4 ○ 'I got rid of the dementia, I only have some other health conditions' Chapter 4 ○ 'I don't have any big problem, but dementia' Chapter 4 ○ Dan & Mary Chapter 4 ○ 'I can deal with that better than I do with the wife thing' Chapter 5 ○ Jane & Alan: 'I was not a pen pusher' Chapter 5 ○ 'Who could that be?' opening vignette Chapter 6	○ Opening Vignette Chapter 3 ○ 'Unexpected Events' Chapter 3 ○ 'Shall we go and visit mum?' Chapter 5 ○ 'It was the police they found Sue' Chapter 6 ○ 'He patted John on the head and he said, oh I am really sorry' Chapter 6

○ Opening vignette Chapter 7		

Figure 4 Overview of vignettes according to type

3.11 Ethics[13]

The study was approved by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 21/12/16. An ethics amendment to approve of doing participant observation in people's daily routine activities outside of the home was granted on 26/04/17.

The participants in this study were a vulnerable group, elderly people coping with multiple health conditions. This required a thorough reflection on ethics. Participants of different backgrounds in different stages of dementia, with different types of dementia, a variety of co-morbidities and in different kinds of spousal care relationships, and their partners of diverse backgrounds and possibly with health conditions, were recruited.

Such variety implied a great deal of flexibility in how the research project has been carried out. People with different types of dementia and co-morbidities will experience different levels of difficulty in, for example, concentration, communication or mobility. Cognisant of this, I tailored the different research methods to the wishes and abilities of the participants.

Working with both individuals and couples, I always took into consideration that the individuals are in a relationship with each other and that interviewing them separately could create stress or tension in their relationship. I discussed with them how comfortable they were with me interviewing them separately and as a couple. Building up a good level of rapport with the couples helped me to discuss the possibility of individual interviews with them and to create arrangements in which this was possible when both spouses agreed; for example, sometimes I would interview one spouse when the other one was in another room, but they always had the option of walking into the interview and joining. Flexibility and dialogue were two very important principles in this study.

[13] For a further reflection on ethical considerations concerning safety, consent, data storage and other practicalities, I would like to refer to Appendix 2.

In every research project it is important to take into consideration the location of the research project, the time of day, the topic and the way the researcher presents herself. When working with people with dementia the consideration of detail becomes even more important. Because of their cognitive impairment it can be more difficult for them to focus and communicate, which can create confusion. To safeguard the wellbeing of the participant with dementia it was important to avoid unnecessary stress by ensuring that the person with dementia was comfortable.

I followed the guidelines of McKillop and Wilkinson (2004): talk directly to the person with dementia, move away possible obstacles like desks, avoid background noises, avoid places in the sun and take the time of day into consideration, make sure the room temperature is comfortable, ask up front if there are topics that can upset the person, have the researcher in a place where the person with dementia feels comfortable. Additionally, I accepted the flaws in grammar, paid attention to metaphors, acknowledged feelings, and tried to search for the message when it did not seem clear (Kotai-Ewers 2011).

People with dementia can struggle with grammar, their stories may seem irrational and they may use metaphors. It was important to keep in mind that conversations might take a different turn than expected and might not be so straightforward. Usually the message had to be extracted. It can be a slower and more intensive process than talking to people without dementia. Taking this in consideration it was easier to adapt expectations and create a more comfortable atmosphere for the person with dementia in which the participant felt acknowledged, listened to and valued. This level of trust and respect made it easier for the participants to share things with me and for me to notice a change in their emotional state or fatigue. When I noticed such a change, I offered to end the visit and pick up on the interview or activity during the next visit.

I also paid attention to my own role in the visits; some people were a bit wary about the visits at first as they reminded them of visits from health care professionals, and they made clear they did not appreciate them in their home. I positioned myself differently in each house, based on the level of rapport I established with each couple and how formal or informal they preferred the house visits to be. For example, one couple preferred me to use their last name while talking to them while the other couples preferred the use of first names. Usually the

couples felt more comfortable with the house visits once a level of rapport had been established.

An exit strategy from the field was important, as I did not want the participants to rely on my house visits once the data collection period had finished. After seven months I had built up a high level of rapport with all the couples; throughout the period of house visits I reminded them of the end date of the visit and the fact that these visits were part of a research project. A month before the last visits I told them we were almost finished and told them that after the visit we could stay in touch if they liked but that I would not be able to visit them every week any more. Three couples showed interest in staying in touch. At the end of the project I printed all the photo diary pictures for every couple and bought them a gift card for 15 pounds together with a thank-you card as a token of reciprocity and so they would have an object that symbolised the end of the fieldwork phase. I included my contact details in the card to enable them to stay in touch when they wished to.

I either mailed them the package or brought it in a visit; I phoned them first to find out which they preferred. In the months after the project three couples initially showed interest in staying in touch; two of them either messaged me or rang me sometimes, and the third couple invited me for a meal. I left the initiative to stay in touch with the couples but sent all of them a new year card after the holidays. I still speak to three of the couples approximately once a month; I haven't heard from the others for months. In general, this leaving strategy allowed me to gradually decrease the frequency of contact. Chapter 8 includes a more elaborate reflection on my exit strategy.

3.12 Summary

In this chapter I gave an overview of the research approach used in the study. I discussed the theory used, methodology, research design, research questions, aims, objectives, validity, reflexivity, triangulation, saturation, the sample, recruitment strategy, methods of data collection, the data analysis process and ethical considerations. In the next part of the thesis I will present my ethnographic data, written as an ethnography including a discussion of literature that is relevant for the themes presented in the different topics in chapters 4 to 7, and a chapter dedicated to reflection on the project and research process, chapter 8.

Chapter 4

‘It Does Not Bother Me’:
Lives and Illness Become Intertwined

Photo 5A Mary in the living room[14]

In Photo 5A, Mary looks at you with a big smile and friendly eyes; she seems happy. Over the years her hair has become lighter and her face wrinkled, but she has kept the same expression as shown in the portrait of sixty years ago. The portrait stands on the side table in the corner, but now the chair is empty.

Dan decided to tell Mary when she came back from the day centre. She always enjoyed it and would be in a good mood, and he did not want to upset her too much. That particular evening when Dan walked up to the mini bus to help his wife get off she said, ‘*I am never going to that bloody place any more’*. Mary never swore, so Dan knew she was very upset. Since Mary was not in a good mood, he called their daughter and told her he did not want to tell Mary right then. The next morning, Dan and their daughter told Mary she was moving into a care home that day. She responded that she had to be strong for their daughter-in-law.

Different events triggered this transition. While Mary’s dementia progressed and she needed more care, their daughter-in-law was diagnosed with two types of cancer. Dan found himself with a dilemma: he liked to travel to the other side of the country to support their son and daughter-in-law but could not leave Mary by herself. On Monday their son rang to tell them that after a long search they had found a

[14] Participants approved of publication

surgeon who dared to operate on his wife. The high-risk operation was scheduled for Thursday. The same day, the nursing home called to say that they had a place available, so together with his daughter he decided the time had come to move Mary into care. Months earlier, Dan had put Mary on the waiting list for a nursing home.

The nursing home was located down the street; they could see the building from their dining room window. It was a big change for Dan and Mary but they got used to it and developed a new daily routine. Dan would visit Mary twice a day, at the end of the visit he would spend a considerable time and effort saying goodbye, and Mary would reply, *'When do you visit again?*'

After five weeks the daughter-in-law's condition had improved somewhat, and the family, children and grandchildren, were able to all visit Dan and Mary on a Sunday afternoon. The nursing home had arranged for them to use the family room and provided tea and biscuits. Dan recalls what a lovely afternoon they had; Mary was able to remember a lot that day and together they shared memories. At the end of the afternoon they said goodbye, Dan promised Mary to visit again that evening, and he and the rest of the family went to his house where he cooked them a meal.

Tears are welling up in Dan's eyes, and for a second, he is not able to speak. He says: *'It was such a lovely afternoon, and in the evening, we held hands while watching television as usual'.* He always found it difficult to leave at the end of the evening; tears are rolling down his cheeks, but he continues: *'I told myself I had to be a bit stronger when leaving her, I was going to see her again tomorrow. So, I stood up and said, "Goodbye love, I need to go home and do some jobs in the house, I will see you tomorrow."* As usual she asked me what time I would be visiting the next day. I went home and called our daughter to reflect on the lovely afternoon'.

He tells me to stand up and walk to the dining room, and he points out the nursing home. That evening while he was on the phone with his daughter, he noticed blue lights flickering at the nursing home site. He told his daughter; *'I think something is going on at the nursing home'*. Thirty minutes later the nursing home rang him to inform him his wife had passed away. Tears are rolling down his face; I give him a hug and tell him it is okay. He takes off his glasses, takes a breath and walks back to the living room. He tells me she had a heart attack; twenty minutes after he left, she stood up to go to the toilet and collapsed on the bathroom floor. They called for an ambulance but she had already died. Mary's death came suddenly and unexpectedly for Dan, and he tells me he feels guilty not having had a chance to say goodbye.

Dan and his family organised Mary's funeral the way she wished. Years before she developed dementia Dan and Mary had discussed their end-of-life wishes. They told each other they did not want to be resuscitated and discussed possible funeral arrangements. Mary wanted her funeral to be joyful: she wanted the visitors to wear bright colours, the choir to sing joyful hymns and the pastor to read some psalms that celebrate life. Afterwards Mary was cremated and her ashes placed in the family grave next to her parents. Mary lost her dad when she was only little and had always been close to her mum. Being put to rest next to her parents was very important to her. Another space in the grave was left for Dan when his time would come.

Dan said he was happy they were able to fulfil Mary's wishes. He also comments that he is grateful that she did not have to experience a further progression of her dementia and was not in much pain when she passed away. He concludes that he is grateful he had spent over sixty years with Mary. I tell him that is extraordinary and I will probably never be able to experience that as I haven't even found a husband yet. He smiles and says they had a great life together; they almost never argued and really loved each other.

Nowadays, the portrait in the corner symbolises both Mary's presence and her absence; it lay on the coffin during the funeral, and now has a prominent place in the living room, as if to remind everyone of her central place in Dan's life.

4.1 Introduction

In this chapter I will discuss the experience of daily life with dementia and co-morbidities and how couples cope with the disruption they experience by creating continuity through their daily routine. The vignette above illustrates how illness and daily life become intertwined. In this chapter I will discuss how illness and daily life are often entangled and how health conditions become an integrated part of daily life and why this perspective matches well the latest developments in the dementia care discourse – dementia and citizenship, dementia and human rights and social health. As presented in the systematic synthesis of the spouse care literature, the process of integration of illness into daily life often creates disruption until a new continuity is developed to cope with the disruption.

People often draw upon their ethos to find ways to cope with illness that fit within their broader way of life; Garro (2011a) showed how a family of Mexican

decent in the US incorporates health in daily life by framing it as part of establishing family-wellbeing, which is an important part of their ethos. People also sometimes draw upon past experiences to make sense of illness and create a place for their coping in their narrative; Garro and Yarris (2009) show how the 'Morris' family copes with their son's ADHD by analysing his past, hoping to gain an understanding of the challenges he currently faces. An interpretivist cultural framework comes into play when people face challenges like illness (Garro 2011b).

I would like to explore the use of this 'cultural framework' further in the context of dementia and co-morbidities by drawing upon the ethos and past experience to make sense of coping with health challenges in daily life further using the dialectic relationship including the concept of habitus as developed by Bourdieu (1977; 1990) in combination with identity theory as a means to better understand the process of disruption and its responsive development of continuity in daily life with dementia and co-morbidities. I will introduce this concept of habitus and identity theory in more depth in Chapter 6. In this chapter I will set out how health and daily life are intertwined and I will briefly refer to the habitus but my discussion of it will follow in a later chapter.

Firstly, I will provide a brief history of the dementia care discourse and discuss how the latest developments, dementia and citizenship, dementia and human rights and dementia and social health, have taken us back to the main question: 'Is dementia an illness or a normal part of ageing?' Afterwards I will illustrate further how illness and daily life are intertwined by taking a closer look at the daily life routine of Dan and Mary and show how the illness and care are integrated into daily life. Thirdly, I will show how current daily life practices have started to serve a medical or care purpose without disrupting other activities or meaning by discussing how religion has offered Aaisha a coping strategy to face many different challenges in life, including making sense of her husband's dementia, and how reiki and reflexology have become a coping strategy for Diane and John. Next, I will show how longstanding traditions of routine medical appointments create continuity for Jane and Alan. Afterwards, I will discuss how continuity and disruption can co-exist and how people negotiate what is 'normal' and 'abnormal' in order to find a new continuity and give meaning to the disruption, using the example of Bob and Sue's coping with incontinence. Later, I will discuss the type of disruption illness creates for which continuity is not easily found, drawing upon unexpected events triggered by

health conditions that disrupted Jane and Alan's Christmas plans. Finally, I will summarise the argument and introduce the topic of the next chapter.

4.2 Background: A Brief History of Dementia Care Discourse

Until the 1970s dementia was identified as a kind of senility and considered to be a family affair (Cohen 2006; Kaufman 2006; Lock 2013). Around this time gerontology developed as a specific discipline which championed equal access to health care and social wellbeing for people of all ages in society and specific attention to health conditions that were most likely to affect the elderly. In general, the elderly and their health care needs had often been neglected in favour of the health care needs of younger people (Thane 2000). The development of gerontology created a space in which dementia could be considered a health condition which affected mostly elderly people and which should be treated.

This medicalisation of dementia reduced the stigma attached to senility and the abuse and neglect of people with dementia by problematising these things (Lock 2013). Although dementia was now viewed as a 'disease', the notion of dementia as part of 'normal' ageing persisted (Cohen 1998). Lock (2013) even predicts that this notion will be adopted by people as long as no cure for dementia is found. The co-existence of these notions creates some ambiguity and makes us question whether dementia is a pathology or a physical process of 'normal ageing' (Kaufman 2006).

The problematising of dementia has created a space in which dementia enters the agenda of governments and pushes health care policy changes. Lock (2013) calls this the political incentive to 'solve' the problem with the aim of raising the profile of research into a cure or prevention, which creates funding streams from both governments and the medical/ pharmaceutical industry. Dementia was called a 'World Health Priority' by the World Health Organization in 2012 (WHO 2012). And the government in the United Kingdom has twice in a row launched a Prime Minister's Challenge on Dementia in 2012 and 2015, making dementia care one of the priorities of health care policy (TeamDementia 2012; DoH 2015); 'Our vision is to create a society by 2020 where every person with dementia, and their carers and families, from all backgrounds, walks of life and in all parts of the country – people of different ages, gender, sexual orientation, ability or ethnicity for example, receive high quality, compassionate care from diagnosis through to end of life care' (DoH,

2015:5).

This incentive to solve a ‘problem’ shaped the development of dementia care, as shown by the focus on diagnosis of dementia using cognitive tests and the measurement of the progression of the disease by assessing the bodily functions that are associated with the pathology of dementia, an approach characterised as ‘defectology’. We are likely to define dementia by the loss of cognitive abilities and behavioural change. Fuchs gives an example of this from a care setting:

One can measure the advance of dementia by the “stills.” The social worker will ask the still questions: Does she still feed herself? Good! Still chew? Good! Still toilet? Well, that’s to be expected. And we have ours: Still like to dress up? Get her hair done? Her nails? Still hang on to her French and German? Yes, a few words, pretty good accent. Still play the piano? Oh yes, the “Anniversary Waltz”, over and over. Still like parties? Oh-ho, does she ever! (Fuchs 2005: 4).

The dominance of the pathology discourse creates a paradox of both raising the profile of dementia as an area for improvement and supporting the initiative to improve support services and health care for people with dementia and simultaneously neglecting the needs of the people with dementia that are not directly connected to health and social care, feeding into a stigma by problematising it. The identity of the person with dementia as a passive patient was created (Bartlett and O'Connor 2010). Defining dementia as pathology and pushing it into the public arena created a space to challenge the paradox.

Kitwood challenged this paradox by starting a discourse on person-centred care, wanting to move away from what he called ‘the standard paradigm’ which was based on the medicalised/pathological definition of dementia (Baldwin and Capstick 2007). The standard paradigm focussed on the loss of bodily functions and in doing so denied the significance of therapeutic value. In addition to that, Kitwood criticised the way dementia was diagnosed, given the limits of neurological research in identifying a clear pathology it was impossible to properly diagnose. He further pointed out that psychological and social explanations for dementia were missing. He criticised the pathology but also accepted it as a reality, while also arguing that dementia is partly a social construct: this makes his position ambiguous. According to him, though, these stances are compatible; he speaks of a dialectic relationship

between the social, the psychological, the environment and pathology; the neurological impairment and malignant social psychology would co-create dementia. He argues that a positive social psychology in combination with the neurological impairment could soften or even counter the impairment, what he calls ‘Rementia’. He used this assumption as the foundation for his advocacy for an improvement in dementia care and his development of person-centred care (Baldwin and Capstick 2007).

Although Kitwood’s original theory of ‘Rementia’ has been widely critiqued for lacking empirical proof and being a theoretical contradiction as it combines positivistic and social constructivist approaches (Baldwin and Capstick 2007), the notion of person-centred care as a type of compassionate care that acknowledges the personhood of those with dementia has been widely appreciated and adopted. It also started a paradigm shift from problematising dementia as a pathology to accepting it as such and moving towards problematising the way we view and treat people with dementia, focussing on the needs of the person with dementia, their personal wellbeing and humanity.

This shift opened up the possibility of problematising more aspects of dementia care, for example the relationships between the different actors in the care setting in relationship-centred care (Nolan et al. 2002). It entailed acknowledging that others, apart from the person with dementia and the carer, play a role in the dementia journey over time (Morhardt and Spira 2013). Later on the definition of personhood as used in person-centred care was challenged. In person-centred care the person with dementia had largely been viewed as a passive actor whose personhood and identity relied heavily on the way others interact with him or her (Bartlett and O'Connor 2007).

Countering this passive view was the idea that the body of someone with dementia is an active carrier of selfhood even when cognitive impairment exists. The concept of the embodiment of selfhood can counter the stigma and negative implications of the neurological impairment that can dehumanise by seeing the body as still presenting the self. Kontos (2004; 2006; Kontos and Martin 2013) has discussed in detail how a focus on embodied selfhood can change the focus from the loss of abilities to who the person still is and what he or she is still capable of. makes us rethink how people express themselves and interact with each other and the world around them; cognition and language are not the only tools for doing so

(Downs 2013). It adopts the idea from philosophy that our interaction with the world entails more than rationality and consciousness (Hughes 2013).This embodied approach challenges the assumption of a loss of selfhood, acknowledging the agency of the person with dementia and the multiple and complex ways in which they communicate their selfhood by interacting with their surroundings.

Another development in dementia research that has put agency on the agenda is the call for participatory research which includes people with dementia as participants and even co-researchers. Research methods and approaches have been developed to acknowledge the agency of people with dementia (McKeown et al. 2010; Bartlett 2012; Capstick 2012; Murphy et al. 2014). This has encouraged a rethinking of capacity and ethics in research, especially in connection with informed consent (Dewing 2007; Sherratt et al. 2007; McKeown et al. 2010; Capstick 2012). Acknowledging the agency of people with dementia opened up the possibility of problematising the assumption that dementia is a disease and has informed a discourse on dementia and citizenship.

In line with this acknowledgement of agency, Bartlett and O'Connor (2007) have suggested that we should view dementia as a disability instead of a disease, changing the perception from a sufferer to a discriminated citizen, who holds multiple identities in society, and who has the capacity and right to establish an active position in society and advocate for equal rights (Bartlett and O'Connor 2007; Bartlett and O'Connor 2010). The dementia and citizenship discourse and its problematisation of dementia as an illness has indirectly brought us back to the major question: is dementia a pathology or part of normal ageing? Instead of accepting the notion of dementia as a 'pathology' it problematises the consequences of the acceptance of dementia as a 'pathology', questioning the identification of the person with dementia as being 'ill', a patient, and as a result of this illness as lacking 'capacity' (Birt et al. 2017).

In line with this development, the WHO (2015) has called for a human rights approach to looking at the daily lives, rights and abilities of people with dementia (Dixon et al. 2018). This approach emphasises the rights of people with dementia to have indiscriminate access to support and care, to being enabled to be actively involved in decision making on their own care, support and living arrangements. Furthermore, it promotes allowing people with dementia to live independently and have access to the right support.

Other researchers in dementia care have suggested the use of the concept of 'social health', with which they emphasise the need to acknowledge the autonomy of people with dementia by focussing on their capabilities and roles in society but also acknowledging the loss of certain other roles and abilities (de Vugt and Dröes 2017; Dröes et al. 2017).

Not only in the dementia research discourse is the ambiguity between dementia as a pathology or a 'normal' part of ageing still relevant. In their daily lives, people with dementia and their spouses also negotiate the 'normal' and 'abnormal' while they experience disruption and try to create continuity. Dementia and daily life are intertwined.

4.3 Daily Life and Illness Intertwined

4.3.1 Loss of a Daily Life

Let us return to the opening vignette. It describes how illness can create disruption in daily life but once a coping strategy has been found a new continuity can be developed. Their daily life is disrupted when Mary has to move into care due to the progression of her dementia, but a new routine is established with Dan's daily visits. This new routine creates continuity for them.

Coping with health conditions and caring are often simultaneous with developing 'new' or altered daily routines (Becker 1997). Illness and daily life are intertwined (Garro 1992; Garro and Yarris 2009; Garro 2011a; Garro 2011b). Living with health conditions and caring are part of day-to-day life (Mol 2006). People often understand their illness in terms of their daily life routine, for example allowing more time for certain parts of their daily routines due to health conditions (Becker 1997). They understand their illness in terms of their changed abilities and changed daily life routine.

The further progression of Mary's dementia, changes in the family and Dan's inability to care for Mary on his own any longer made Mary move into care. This ended the daily life routine they had established at home, but a new one was created in the daily visits of Dan to the nursing home. Daily life and Mary's health conditions were intertwined for Dan and Mary; even when she moved into care they found a daily routine that enabled them to continue to share their daily lives together. Eventually, when Dan dies they will even lie beside each other in the graveyard.

When Mary passed away, it meant not only the loss of a partner and soulmate but also the loss of a particular kind of daily life routine and lifestyle with Mary at the centre. It also meant the end of a marriage and its vows to care for each other, the loss of a purpose. Although Dan can still do most of activities he used to do with Mary on his own, it is not the same for him or for others around him, as illustrated by the following event:

Dan is walking up to his car when a neighbour approaches him: *'Excuse me, I am sorry to ask, but how is your wife doing?'* Dan: *'Do we know each other?'* Woman*: 'I live down the road and always noticed the two of you together when you were going somewhere, lately I notice you are on your own. Is your wife not well?*'

It took Dan a couple of months to get back on his feet and find a daily life routine again, which illustrates well how caring is much more than a 'burden' (Daniels et al. 2007; Hellström et al. 2007; Botsford et al. 2012); the continuity in Dan's life was disrupted by losing Mary. But being able to fulfil Mary's end-of-life wishes created a type of continuity that helped Dan cope with the disruption and gave him some consolation.

4.3.2 A Typical Friday

9.00 a.m.: the alarm clock bleeps, Dan wakes up and looks to see whether Mary is lying beside him. Sometimes Mary goes to the bathroom at night and cannot find her way back to their bedroom; instead she sleeps in one of the beds in their daughters' former bedroom. Dan and Mary have lived in the same house for over forty years. They moved there when they were still raising their children and kept most of the bedrooms in the same state although their children had moved out over thirty years ago. Dan woke Mary up: this morning she was sleeping next to him. She pulled herself up using the handle next to the bed and got out of bed.

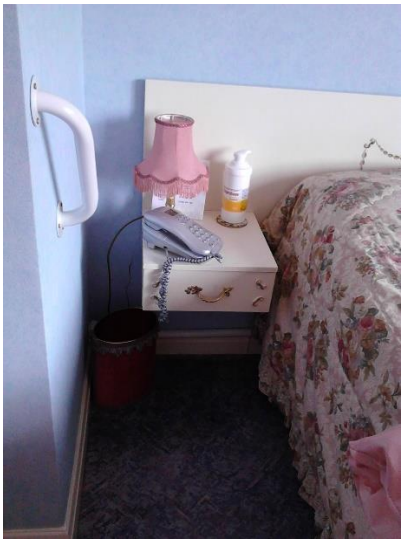

Photo 5B Dan & Mary's bedroom[15]

Together they walk to the stairs. Depending on how Mary feels she will take the stair lift or climb down the stairs by herself. Dan encourages Mary to avoid using the stair lift when possible, as he finds it important that Mary gets some exercise. This morning Mary takes the stair lift, and Dan descends the stairs and waits downstairs.

Mary chooses to ride the stair lift but does not know how to turn the chair towards her. Dan tells her where she can find the handle and how she should turn the chair. Mary sits down on the chair without fastening the seat belt or unfolding the tray to let her feet rest. Dan needs to remind Mary to push the switch to make the chair descend. At first Mary cannot find the switch, and when she does she seems confused about how to push it. Dan makes arm gestures showing how to push the switch, and a bleeping sound marks the start of the chair's movement. Dan tells Mary to keep pushing the switch till she gets all the way down the stairs. When the chair arrives at the bottom of the stairs, Dan turns the chair and gives Mary an arm to get up.

[15] Participants approved of publication

Photo 6B Stairlift[16]

When they are both downstairs Dan and Mary walk into the kitchen to have some breakfast. Dan tells Mary to sit down at the table while he prepares some coffee, two bowls of breakfast cereal and two glasses of water. He puts everything on the table, takes a seat next to Mary and gives her her medication. They have their breakfast and take their medication. Mary finds it difficult to swallow the pills and Dan hands her some extra water. After breakfast he cleans the table and dishes and tells Mary it is time to get dressed. Mary climbs the stairs this time, holding on to both the handrail and rail of the stair lift. Dan follows behind her.

They have made several changes to the bathroom. They had a special toilet seat and a walk-in shower installed, so Mary would be able to keep using the bathroom without the risk of slipping. When they walk into the bathroom Mary expresses anxiety about using the walk-in shower, so Dan offers to wash her in front of the sink as he does almost every morning. Their children encourage them to ask for someone to come to the house to provide personal care in the morning, but Dan does not want this. He is happy to care for Mary; they are married, and he took a vow to care for her till the end. He once told me: *'We are not embarrassed with one another nowadays. These things have to be done, it is part of your life and the love we have for one other, we both need each other's help sometimes'.*

Photo 7B The walk-in shower[17]

[16] Participants approved of publication
[17] Participants approved of publication

The evening before, they chose Mary's outfit for today, a purple cardigan, light trousers, black ballet flats and a flower necklace, and laid it out on one of the beds in one of the spare bedrooms. Dan and Mary are especially pleased with the shoes; because of Mary's diabetes she holds a lot of fluids in her legs and feet, and consequently she did not fit any of her old shoes any more. Also, she has difficulty walking because of her arthritis and hip and knee problems, and comfortable shoes like these help her to keep moving. A friend of theirs had told them about the particular brand and advised them where to buy them. They were a bit more expensive than what they would normally pay for shoes, around eighty pounds, but they felt like they were worth every penny.

When they are both bathed and dressed they go back downstairs and take a seat in the two chairs in the dining room, looking over the garden, enjoying the birds and flowers. The phone rings, and Dan walks to the hallway to answer it. When he comes back Mary says*: 'Is it not nice that people call us here? We do not even live here'.* She stands up and points out to a little bird flying by and says, *'That bird does not really know us as we are only staying here, but what a wonderful garden'.*

Photo 6A View of the garden[18]

It is almost lunch time. Dan and Mary go to the kitchen and prepare some lunch. The microwave bleeps, the buns are ready; Dan puts them on a cutting board and cuts them open, leaving them to cool down. He warns Mary that they are still hot. He takes the margarine and hands Mary a knife. He encourages Mary to spread the margarine on the buns. She decides to put margarine on both parts of the buns.

[18] Participants approved of publication

Then she tries to figure out which parts of the buns belong together and tries to pair them up as a bun. Dan tells her it is all right, puts the buns aside and tells her to cut some of the cake. Mary cuts the cake in slices and starts to butter them. Dan tells her she does not have to do that. He instructs her to put the cake on different plates and put them on the table. In the meantime, Dan puts the food, drinks, cutlery, plates and glasses on the table. Dan and Mary sit down and have their lunch.

After lunch they are going grocery shopping. Dan likes to keep enough food in the house, especially in the freezer, so they will always have something to eat even when they do not have time to go grocery shopping. They will first go to the Asda, where they will buy most of their groceries, and afterwards they will go to the M&S to buy some additional products and to have a cup of tea with Mary's cousin and her husband in the café. They get in the car and Dan drives them to the shops. Dan learned to drive when he was 35, encouraged by his employer; Mary never drove a car. The car is important in Dan and Mary's life. They drive everywhere nowadays; Mary's mobility problems disable her from walking anywhere except short distances within their home.

Dan parks the car in a disabled bay close to the entrance of the centre. Since last year they have had a blue badge, allowing them to park in any disabled bay available, enabling them to keep going places together. They first go to the Asda; when they enter the shop Dan searches for a chair at the tills for Mary. He tells Mary to sit down and wait for him while he does the shopping. After Dan pays for the groceries and loads them in the car they set off to the M&S. They walk through the shop together, giving Mary the chance to choose some products she would like to buy. They finish the shopping with a cup of tea in the café with their relatives.

Photo 7A Grocery shopping[19] Photo 8A Mary having a cup of tea[20]

They spend about two and a half hours at the shopping centre; when they come home it is time for Dan to prepare a meal. Around 7 p.m. they will set off again to meet their friends from church at the club. Every Friday evening their group of friends meets at a local club for some drinks, a chat and a raffle. They have known the friends in the group for almost forty years, and they all know about each other's health and wellbeing. Dan explained: '*Well, discussing health is a fairly big topic of conversation among older people is not it, you know. I've got an ache and pain here, or one there, or something like that. Or I have been to the doctor for this. Not the only conversation by any means, but invariably it does arise during the course. They're all in the same boat, usually'.*

They offer each other help when needed, for example some of their friends have offered to sit with Mary on a Wednesday morning while she waits for the bus to pick her up for the day centre; this way Dan can go to the men's forum meeting.

Photo 9A Friday night at the club[21]

That evening at the club they all gather around a big table and order some drinks. Mary sits at the middle of the table surrounded by friends. She does not really talk. When others ask her a question she answers, but she does not initiate conversation. When Mary wins some food in the raffle Dan encourages her to talk about the

[19] Participants approved of publication
[20] Participants approved of publication
[21] Participants approved of publication

products she won. Some of their friends try to make conversation; nevertheless, their attitude towards Mary seems to be different than before. They only briefly talk to Mary but mainly turn to Dan.

4.3.2.1 the daily routine

Waking up, getting dressed, having breakfast, having a cup of coffee, preparing lunch, going grocery shopping, having dinner and meeting friends in the pub: many of us would recognise these activities as part of our day-to-day routine, and for Dan and Mary it is no different. They have had the same Friday routine for many years. Illness did not change the complete routine but made them make adjustments to continue the routine; Dan had to take up the leading role in most activities, for example preparing meals, instructing Mary on how to do certain things like buttering the buns, helping Mary to get washed and dressed, buying more comfortable and expensive shoes for her, finding a chair in the supermarket, applying for a blue badge, and encouraging Mary to take part in conversations in the pub.

These adjustments help Dan and Mary to continue to share the same activities they have always shared but also make them share activities they normally would not share, like Dan washing Mary. Dan rationalises providing personal care as part of 'being married': it is part of the vow he took, his ethos. In this case both Dan and Mary feel okay about these changes, although in other relationship these changes can create clashes, as I will discuss in detail in Chapter 6. The adjustments that enable the continuity of these daily life experiences create a situation in which 'taken for granted' activities can be carried on. Still, adjustments need to be made to the environment to enable this favourable outcome of the dialectic relationship.

Not only does this description of their daily routine show how the changes in abilities due to health conditions seems to be integrated into their daily life, it also shows how dementia in combination with other health co-morbidities ask for further adjustments and make the care more complex and intense (Mountain and Craig 2012; Newbronner et al. 2013). Dan and Mary had a stairlift installed so Mary could still go up and down the stairs despite her mobility problems, but the dementia made it difficult for her to operate the lift and Dan has to give extra attention and support to Mary when she descends the stairs.

4.3.3.2 Adjustment to the environment: The home

Adapting the home to the loss of abilities has become part of 'normal' daily life. Dan and Mary wanted to continue to live in their house as long as possible and made adaptions to the house to make this possible. They had to finance some of these adaptions themselves, while others were paid for by the local council. They financed the stairlift and walk-in shower themselves, and the local authority provided them with the special toilet seat and the handle next to the bed. When I ask them whether they feel like these alterations have changed the character of the house, Dan answers: *'Well, no, not particularly. I mean, it is something which is there and is useful to us, but it can be quickly altered if we sold the property and someone else wanted to take it off. It is not permanent, is it?'* Dan explains the temporality of the need for these alterations and how they change with their needs.

The confrontation with the loss of abilities that these objects facilitate (Angus et al. 2005) does not seem to bother Dan; on the contrary they represent who they are and their needs. He demonstrates a level of acceptance of the loss of abilities and a coping strategy in daily life. Furthermore, their financial situation allowed for deciding to install these adaptions themselves (Angus et al. 2005), creating a sense of empowerment to enact on one of their most important values of their common sense: take responsibility for yourself and take care of each other. Also, it enables Dan to fulfil part of his aspiration to take care of his family: providing to meet their needs.

Government policy encourages elderly people to stay at home longer, caring for each other in the home (Sixsmith and Sixsmith 2008). They like to encourage and support the elderly to 'age well': continue their daily life being involved with the community as long as possible (Ridley-Ellis 2011; JSNA 2015; Volpe 2018). It is generally assumed that staying an active member of the community creates a higher quality of life. Especially when someone has dementia, living at home as long as possible is recommended because the familiar environment functions to reassure (NHS 2015). Although national health policy states that ageing in place is important for people with dementia as the home environment is reassuring, in this case it seems to confuse Mary and put tension on the couple's relationship. Mary does not seem to recognise the house as their home any more, although they had spent most of their lives living in this house, over forty years, and she cannot always find the way

back from the bathroom at night. She also seems to think they are only visiting the house, commenting how nice it is that people call them on this address.

The loss of these memories creates an inaccessibility of the habitus. The dialectic relationship between the habitus, body and environment does not create the familiarity and its corresponding expected behaviour: feeling at home, knowing your house and being able to walk around without having to think about it. Instead it creates confusion and upset and shows Mary's inability to find her way in the house. Furthermore, this inaccessibility of the habitus and corresponding embodiment create tension between Dan and Mary as they challenge the shared common sense on which their relationship is built. I will further elaborate on this in Chapter 6.

Photo 8B Special toilet seat[22]

The alterations to the house only partly served their goals. Although the stairlift enabled Mary to go upstairs when she was unable to climb the stairs, she was unable to use the stairlift independently. Also, anxiety prevented Mary from using the walk-in shower which had been installed mainly to help her get in and out of the bath tub without slipping. However, some other alterations did serve their purpose. Mary was able to go to the toilet on her own, and she used the handle next to the bed to pull herself up. Also, the rail of the stairlift served as an extra handrail for when Mary wanted to climb the stairs herself. Although they made alterations to their house to enable them to stay at home longer, they could not prevent Mary from having to move into care.

[22] Participants approved of publication

Now I have shown how daily life and illness are intertwined and how, by making adjustments to daily activities and the environment, the continuity of the daily routine can be sustained. As for how this continuity is challenged by the inaccessibility of part of the habitus, I next discuss how sometimes coping with illness does not need adjustment but a reappreciation of current daily life activities.

4.4 Relying on Established Coping Strategies

4.4.1 Questioning God

'God says you are best person' reads Hamid out loud when I ask him what he is reading. He points out the Arabic words and asks me if I can read Arabic. I tell him I cannot. He starts to translate some of the words and repeats: *'God says you are best person'*. He turns the page and starts to pointing out different names for God, slowly pronouncing the names. It is as if he wants to teach me about his religion and its important figures. Hamid used to be a primary school teacher and he seems to enjoy teaching me.

After lunch and midday prayers Hamid always reads a couple of prayers and/or poems out of the Quran. Most days Hamid goes to the mosque for these midday prayers while Aaisha prays at home. Aaisha also used to visit a weekly 'women's' group in which she discussed the Quran with other women from their neighbourhood. Their daily prayers offer them continuity; they will always try to keep an hour after lunch free to pray. When we set a new appointment for a visit they always make sure it takes place after the midday prayer. When winter time turned into summer time, their prayer time changed and they asked me to visit later in the day from that day on. During Ramadan, they asked me not to pay them any visits for a month.

Through changes in life they have always held on to their religion. They moved country, left most of their friends and family behind, had to find a new home, build up relationships in the community, learn a new language, try to understand a different culture, adapt to a new climate and change their lifestyle, but they could hold on to their religion and continue the daily routine of prayers. Furthermore, the Quran offered emotional support when Aaisha reflected upon losing her brother a couple of months ago; she said: *'I was very sad, but God took him'.* As they underwent all these changes, religion offered them a guide; Aaisha comments*: 'The*

Quran never changes, I like how the Quran explains why and how things happened to the people in the Quran'. The Quran offers Aaisha examples of how and why certain things in life happen. These examples used to give her guidance about how to understand her own life and how to cope in changing circumstances.

Islam has a central place in her life: she prays five times a day, visits a women's group to discuss the Quran once a week, watches speeches of a popular Pakistani Mufti on television and comments how the Quran is her favourite book. Furthermore, she likes to live her life according to the Quran; for example, she covers her hair when she goes outside, eats halal and gives money to poor people, in order to be able to explain to God why she lived her life the way she did upon arrival in the afterlife. When I ask her about the future she says: '*My future? Yes, inshallah my future is all right'.* The future is in God's hands; he can take away her worries but also give her worries.

The Quran used to offer her a continuous source of support and guidance to make sense of everyday life, and these days it is no different. However, Aaisha does more often find herself asking questions to god to understand the challenges she has to cope with. At first sight it seems like the Quran is not able to provide the answers, guidance and support that eases her worries any more. Aisha comments: *'Now is a big change. Now, I do not know about God, I mean Hamid left. My future is over now. Now, I worry about my husband...now it seems to go little bit better with him...but I do not know, is the worst part behind? Slowly, slowly things seem to get worse again; he does not like to go out, he forgets more thing, his preferences have changed, he started to dislike a lot of things'.*

4.4.1.1 Is her habitus questioned?

In the past religion helped her to cope with the disruption and changes in life caused by emigrating to England. The continuity it created confirmed her belief but the current challenges she faces with Hamid's health conditions and her care role make her ask questions to god. She would like to understand why they are facing these challenges. She hopes that religion will be able to provide the insight and meaning for these changes as it did for her when faced with other challenges in the past.

Religion does not seem to be able to create the continuity in daily life that it used to any more. Not only does Aaisha find herself in a phase of questioning, but the health conditions also interfere with their practical experience of the religion.

Hamid is no longer able to go to the mosque on his own to pray; Aaisha needs to take him and someone at the mosque needs to walk him home. Sometimes he forgets about prayer time or does not want to go to the mosque any more. When Hamid does not want to go for prayers in the mosque, Aaisha needs to keep an eye on him and loses the moment in the day she would have had to herself to pray and do other things, like having a shower. But when Hamid wants to go to the mosque it also takes away from Aaisha's prayer time as she needs to walk him there even though the mosque is only up the road. Aaisha cannot attend the women's groups in which she discusses the Quran with other women in the community any more, as she needs to stay home to care for Hamid. For other couples, some of their past coping strategies fairly easily translated to the new situation, such as Diane and John's use of reiki and reflexology.

4.4.2 Reiki and Reflexology

Diane started going to reiki sessions about twenty-five years ago. She had started sessions with a personal trainer who asked her to do exercises which she just did not seem to be able to do; 'The stupid Swiss ball. You know, they want you to kneel on it, and then they also want you to do things with weights, it is all about balance and floor stuff. I could not do it and was getting really annoyed with myself, because I thought this is stupid, you should be able to do that. And I went for my reiki and I went straight to a gym session and I just got on the ball and balanced on it, and just did all the exercises', Diane recalls. At first, she went to reiki to cope with her frustrations at the gym but she enjoyed the sessions so much she kept going and it became a central coping strategy for any type of stress and frustration in her life.

She also tried out reflexology and tells me: '*The first time I went, I only realised she had finished when I heard her washing her hands, but it felt as if her hands were still on my feet. You know, it was really … And another time, I felt as if I had actually lifted'.* Because Diane had had such positive experiences with reiki and reflexology and had got to know the women who deliver these sessions well, she told them about the changes in her daily life concerning John's various health conditions. They suggested that reflexology would possibly help John to relax and give some relief for his cellulitis and lymphoedema.

'You do enjoy going, do you not? He likes having his feet massaged', says Diane to John. '*I like it, I must admit',* replies John. Reflexology has become both a coping strategy and an enjoyable relaxing activity in the weekly routine of John and Diane. In the meantime, Diane kept going to her own reiki sessions and used it as a strategy to cope with the stress of the day-to-day caring activities. Diane was able to use coping strategies from the past to cope with current challenges, and her past experiences helped her to find a coping strategy for her husband; her habitus helped her to cope with these challenges.

While in the example above Diane's habitus helped her to cope with new challenges, medical procedures and appointments can also become part of the habitus after they have become routine over a long period of time.

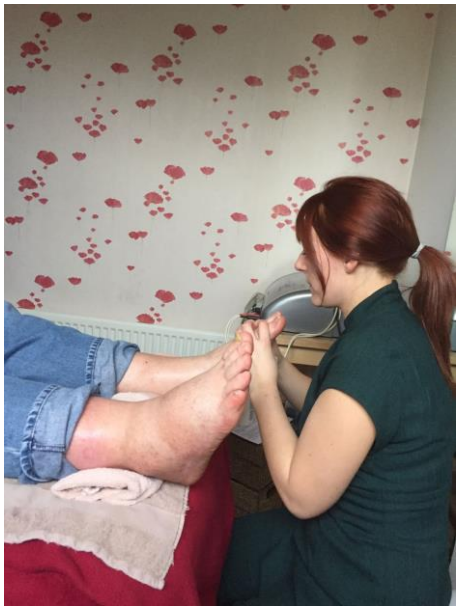

Photo 10A 'John having reflexology'[23][24]

4.4.3 Routine Medical Appointments

Jane and Alan have weekly hospital visits. Every Tuesday they visit the ulcer clinic for the treatment of the ulcers on Alan's legs. At the clinic they, the nurses take off the dressings, wash his legs with special soap for sensitive skin, and put on new dressings. When I ask them about their experience of this weekly appointment Jane asks Alan: *'You have got so many friends there, have you not ? Everybody knows*

[23] Description provided by the couple in their photo diary
[24] Participants approved of publication

you there.' Alan replies, *'Well we go back over 30 years, once you got them it is not easy to get rid of them again. The last time I was free of ulcers it only lasted about two weeks.'*

Alan has lived with ulcers for over thirty years now and has had weekly hospital visits ever since they started. He knows most of the people who work at the clinic and they take a genuine interest in Alan's wellbeing. At their clinic visit yesterday one of the nurses they have known for a long time expressed her concerns about Alan's continuing weight loss; she asked Jane: '*Do you drive?'* Jane replied: '*No, I do not'.* Alan commented: *'I used to drive us but the doctor told me to stop driving two years ago, so I stopped.'* The nurse asked Alan: '*Would you drive Jane around if you knew that you almost ran out of petrol?'* Alan answered: '*No, I would not.'* The nurse continued: '*Your body is like a car, it needs its petrol, you will have to eat and drink.'* The weekly visit to the ulcer clinic has become part of their weekly routine and they talk about it as if they go to see some friends once a week. The medical personnel at the clinic know them well and show an interest in their day-to-day living, as in the vignette above in which the nurse talks to Alan with an example that appeals to him and his habitus to encourage him to eat and drink more. Alan always used to drive his wife places, that was part of daily life routine, so the nurse hopes this metaphor will help him to understand he should try to eat and drink more.

The metaphor appeals to Alan but also confronts him because it refers to an activity he always used to do. It also confronts him with the fact that he is not able to drive any more. In this way, a metaphor referring to past routines to appeal to a certain type of continuity also creates a confrontation with the recent disruption of this continuity by his health conditions.

So far, I have shown how the habitus can be used as a way to cope with illness in daily life through creating continuity. Past experiences and past coping strategies are not always sufficient to create continuity in day-to-day life with illness. Sometimes a change in 'ethos' has to be created, a re-negotiation of normal and abnormal, in order to sustain continuity without too much disruption.

4.5 Disruption and Continuity: Negotiating 'Normal'

4.5.1 'It Does Not Bother Me': The Development of a 'New' Normal

One afternoon when I was visiting Bob and Sue, they suggested going and visiting their sister-in-law for a cup of tea. Bob asked us to get ready and walked to the hallway to get his shoes. '*Do you have your handbag?'*, I ask Sue. She does not respond and we walk to the back door. Bob asks her again, *'Do you have your handbag?' 'No, I do not',* Sue responds. *'Could you get it?'* Bob replies. Sue walks back into the living room and picks up her bag. When she arrives back at the door Bob asks her, *'Do you have a pair of pants in there?*' She looks down and tries to pull up her skirt, as if trying to look underneath it. I stop her: *'That is all right, do you have pants in your handbag?'* Bob corrects me: *'Please let her check, these days you never know, sometimes she forgets to put on underwear'.* Bob picks up Sue's handbag and unzips it in order to look for a spare pair of underwear. *'There is no pair of pants in there, we should take a pair with us these days. Sue, could you put a pair in your bag?'* says Bob.

In order to take a spare pair of pants with her, we first had to search for one. Sue often misplaced objects in the house and many things went missing. Sometimes she seemed to have a habit of putting objects in the same unusual place; she often placed pairs of pants under the seating cushions of the sofa. I had noticed underwear under the cushions before; I lift one of the cushions but no underwear this time. Sue climbs the stairs to continue her search upstairs. Bob looks on the radiator in the hallway and finds three pair of pants and a pair of tights hidden under a coat on the radiator. *'I found a pair of pants, can you come back down so we can set off?'* shouts Bob from underneath the stairs. Not much later we set off to visit their sister-in-law.

Their sister-in-law welcomes us and tells us to sit down in the living room while she goes to the kitchen to make us a cup of tea. After we have had a cup of tea and a chat I smell an unpleasant scent. Sue asks, *'Where is the toilet?' 'It is upstairs, the first door on the left. You can find the stairs in the hallway, around the corner of this room',* answers her sister-in-law while she points out the direction to the hallway with her index finger. Sue has visited this house regularly for the last forty-odd years but lately she needs directions in order to find the bathroom.

After a while the sister-in-law says, *'I will go and check up on her'*. When she walks back into the living room she asks Bob, *'Did Sue bring an extra pair of pants?'*

'Yes, I told her to put a pair in her handbag', replies Bob. He opens her handbag to search for the underwear. *'I cannot find a pair, how is that possible?'* Although he found a pair on the radiator before leaving home he forgot to put them in Sue's handbag after she had descended the stairs just before we left. In the meantime, Sue walks back into the living room. *'I am sorry, we will go home so Sue can get changed',* Bob says. *'You never bring a spare pair while this happens almost every visit',* complains the sister-in-law. *'Can Sue not borrow a pair of yours?'* I ask her. *'I have often lent her a pair but she never returns them you see',* replies the sister-in-law. *'I need to keep a little pile of clean ones for myself. I have a bag [stoma] and sometimes it leaks multiple times a day',* she explains. '*Maybe Sue can leave some of her underwear here, just in case, she seems to visit often'*, I reply. The sister-in-law does not answer but climbs the stairs. When she descends again she is holding a pair of pants with a pad in it. *'Sue could you follow me upstairs? You could borrow these',* she says to Sue. After Sue gets changed we go back to Bob and Sue's house.

When we arrive at Bob and Sue's home we go to the living room to have another cup of tea. While we sit around the dinner table Bob gets up to take his tablet out of the drawer of the cabinet. He places it on the table, switches it on and asks: *'Could you show me how I can buy flight tickets online? I am thinking about taking Sue on a holiday to Spain, like we always used to, if she wants to'*. I turn to Bob and tell him which website he could try. While Bob seems to struggle to find out how to go on the Internet and look for the web page, I give him some instructions and kept my eye on it. In the meantime, Sue gets up from the table and decides she would like to change her outfit. Bob notices and says: *'This is not a nudist camping, what should Denise think of this?' 'It is okay, these things happen, I used to work in a nursing home',* I reply. Bob concludes, *'Oh, okay, so you are used to things like this'.* He picks up his tablet again and tries to open the web page, and I advise him to use a different server. Meanwhile, Sue continues to get changed, taking no notice of our presence in the room.

After Sue gets changed she goes upstairs. I use Sue's absence as an opportunity to ask Bob about the past events of today. *'How do you feel about what happened today?'* I ask. Bob says: *'It does not bother me, especially not at home, she can get changed'*. *'Maybe it would help her if she would wear pads or some incontinence pants, it could help to avoid situations like the one today, and it will*

mask the scent. She usually wears a skirt so no one will notice', I suggest. *'She will not wear them, she will say something like, I am not crazy!'* replies Bob. He continues: '*I know she tries to cope with it her own way. I always hear her going to the toilet around 4.00 a.m., and when I changed the sheets of her bed last week I noticed she was sleeping on a couple of towels'*. A couple of months earlier, Sue had decided she liked to sleep on her own in another room. I tell Bob: '*There are special mattress covers and absorbing blankets you could get'. 'I do not know about these things',* replies Bob. *'Maybe you could ask the social worker when she comes to visit',* I suggest.

4.5.1.2 Normal/abnormal, continuity/disruption

Checking whether Sue is wearing underwear and has got a spare pair of pants in her handbag have become 'normal' parts of their daily routine, while for me these 'acts' like pulling up your skirt to check if you are wearing underwear seemed 'abnormal'. Storing underwear underneath the cushions of the sofa or at other random places instead of in the wardrobe seemed odd as well, but for Bob and Sue it had become common, and expected. Having to delay their visit in order to search for a pair of pants did not seem to bother them. They had become used to these 'new routines' and the time they took.

Their sister-in-law seemed equally used to these new routines; she provided Sue with elaborate instructions on where to find the bathroom although Sue had visited her house regularly over the last forty years. And even though Sue had had accidents at her house before, she still welcomed them as usual and even went to the bathroom to check up on Sue when it was taking a while. She has a type of incontinence herself and has the products to cope with it. Not the fact that Sue is sometimes incontinent while visiting seems to annoy her but the fact that she does not bring an extra pair of underwear with her and does not wear the pads or use the products available to cope with it.

Sue does know she is incontinent and tries to cope with it on her own, bringing the extra pair of underwear in her bag, sleeping on some towels and waking up in the early morning to go to the toilet. But she seems to resist using the professional products available to cope with incontinence as she seems to think these products are designed for 'crazy' people. Bob seems to accept the situation as

he does not want to upset Sue. He has become used to it; it is part of his habitus, but Sue struggles to accept this new reality and will not accept specially designed products. She copes with the challenges the way she might have coped with them in the past.

Although Bob does not seem to be ashamed or uneasy about Sue's incontinence, but still takes her places, just asking her to bring spare underwear, and even encourages her to check whether she is wearing underwear, he does seem to feel uneasy about Sue undressing in the living room, especially when they have visitors. But when I comment that it does not bother me, he seems to feel more at ease about it as well. Sue changes outfits multiple times a day in different rooms of the house, and Bob has become a daily spectator of this routine; it has become 'normal' to him. But he does know that other people might experience it as 'abnormal'.

Although many changes seem to have taken place in their daily life, Bob tries to keep some activities they always used to enjoy: visiting their sister-in-law, going on holiday to Spain. I encourage him to talk to a social worker, because although the professional incontinence materials might be a bit disruptive, they could also help Bob and Sue to continue their routine by making the routine easier when stressful situations, like having to go home early from a visit after Sue had an incident, are avoidable.

Although disruptions are apparent in this example, Bob and Sue seem to find a way to 'normalise' the changes and continue their daily routine. Continuing daily routines and normalising what first seems 'abnormal' helps to create continuity in daily life (Becker 1997). Sometimes finding a way to continue the routine is difficult or even impossible, especially when the disruptions come quite suddenly.

4.6 Illness and Disruption of Daily Life

4.6.1 Unexpected Events

'We went to Manchester for Christmas, my niece rang up – Alan is her godfather – and asked us if we would like to visit them. This is a picture of their two little girls, Alice of eight and Jessica of five, who Alan calls his two liver birds. We had a lovely Christmas Eve, but on Christmas Day Alan started to be ill, on Boxing Day morning he was taken into hospital in Manchester. He had a heart attack and pneumonia and spent eight days in hospital. In January he was admitted hospital again in our home

town, and three weeks ago he was in hospital again, third time in a row. Last time he went in with pneumonia again, so he has been really run down. He has been on antibiotics and goodness knows what, but we get by' (Jane).[25]

Alan's health conditions sometimes take over daily life; Jane and Alan arranged to spend Christmas with family but their plans were disrupted when Alan had to go into hospital. Jane and Alan can make plans, but never seem to know when the health conditions ask for urgent attention. All couples in the study live with this uncertainty to some degree, depending on the co-morbidities one of them has. The more co-morbidities and the greater the complexity of the different health conditions the higher the likelihood that unexpected medical emergencies will take place. All couples try to keep involved in the activities they always used to do and plan activities as usual although they know they might be disrupted unexpectedly.

4.7 Summary

Health conditions often become an integral part of a daily life routine; many of the possible disruptions can be coped with by making adjustments to activities or including new activities in the daily routine to create continuity. Sometimes these adjustments are relatively easy as they do not question the overall meaning/purpose of the routine, as described in a typical Friday. They only need to change the meaning of current activities, like Diane and John's use of reiki and reflexology. Or they have become a routine in themselves, like routine medical appointments over a long period of time. Other times, these adjustments are more challenging as they make the people renegotiate what is 'normal' which makes them change their ethos. The unpredictable nature of health conditions can cause unexpected disruptions of daily life for which a continuity that helps the people cope cannot be found. Or these changes not only disrupt the daily life routine but also make them question their habits, coping strategies and ethos. Keeping up a daily routine and managing dementia and co-morbidities is challenging (Mountain and Craig 2012); many different challenges and disruptions have to be coped with in order to continue a daily life routine. Moreover, it is hard to change routines especially when these changes are forced upon one by an illness instead of part of a choice (Mol 2006).

[25] All names are pseudonyms including the names of the cities.

Which events, changes and adjustments are most disruptive and how to create continuity depends heavily on how people have coped with challenges in the past and how they interpret the current changes and give meaning according their habitus. The habitus is influenced by dominant ideas in society that influence our ethos, like stigma. In the next chapter I will discuss how the stigma surrounding dementia and certain other health conditions influences the way people cope with these illnesses in daily life.

Chapter 5

‘I Never Discuss with Her that She Has Got Dementia, I Just Call it Memory Loss’:

Coping with Stigma and Negotiating Identity

‘What was a turning point in your life?’, I ask Bob. Bob and I are sitting around the table in their living room to talk about his life history, Sue is upstairs getting changed. *‘This,’* answers Bob. *‘The onset of the dementia?’*, I ask. *‘Yeah. I never mention that to her. No, no! She will just say, “I have not got that”’*, he replies. He lowers his voice and says: *‘She might be listening, she will be getting changed I presume’*. He seems scared that Sue will overhear us talk and become angry. He continues: *‘And all this about people coming in to help, it is not my idea’*. *‘You mean the social workers?’*, I ask. *‘Yes, it is not my idea’,* Bob confirms.

5.1 Introduction

As discussed in the previous chapter, making sense of the dementia and co-morbidities in order to create continuity is part of coping with the disruptions in daily life and the relationship that have been created by the dementia and co-morbidities. When people make sense of dementia and co-morbidities this process is influenced by dominant ideas about dementia in society. There has been a lot of attention to dementia in the media in the last couple of years, next to the well-known negative media coverage on dementia represented in titles like ‘Dementia is the leading killer of women’, ‘Dementia is the biggest killer for women’, ‘Alzheimer and Dementia are second biggest killer in Australia’(Hope 2014; Sabin 2014; Davey 2015). Organisations like the Alzheimer’s Society and DEEP (the dementia engagement and empowerment project) and dementia advocates like Wendy Mitchell have campaigned for a more positive representation of life with dementia (Bartlett 2014a; Bartlett 2014b; Deep 2015). Wendy Mitchell keeps a daily blog about her experience of living with dementia on her website where she states:

It will hopefully convey the helplessness of those diagnosed with dementia, as there is no cure – the end is inevitable. However, I am also hoping I can convey that, although we’ve been diagnosed, people like me still have a substantial contribution

to make; we still have a sense of humour; we still have feelings. I am hoping to show the reality of trying to cope on a day-to-day basis with the ever-changing environment that dementia throws at those diagnosed with the condition. Living as well as you can with dementia is all about adapting. Adapting to new ways to enable us to live better for longer with dementia. What I want is not sympathy. What I want is simply to raise awareness (Mitchell 2018: 1).

Her blog shows she feels the need to present a contra voice to the negative media coverage on dementia. Especially the sentence 'What I want is not sympathy' shows how she wants to change the discourse and representation. She wants to raise awareness and show that a positive attitude towards living with dementia is possible. In England she has become a well-known person and she even recently published a book on her daily life experience. Although Wendy and other people with dementia and organisations who advocate for a positive attitude towards living with dementia have a lot of media presence lately and are known by a big audience, a stigma still exists. Some people with dementia are not able to or do not want to accept the diagnosis, as the example of Sue at the beginning of this chapter illustrates.

In this chapter I will show how the medicalisation of dementia provides care and support services but also creates a stigma of being 'ill' and how the couples negotiate their identity as an elderly person, person with dementia and co-morbidities or carer, depending on context. First, I will provide a brief overview of the ideas about dementia and stigma within the dementia care discourse. Secondly, I will discuss how the couples in my study cope with the stigma of dementia and how they experience it, drawing upon examples from my fieldwork. Afterwards I will discuss how the couples' acceptance or rejection of dementia influences their access to support and care, as the example of Bob and Sue illustrates. Finally, I will discuss how the couples create continuity between their current daily life and future by accepting or rejecting the diagnosis.

As I have shown in the last chapter, dementia and co-morbidities are intertwined. People negotiate the normal and abnormal every day; applying the dementia diagnosis and identity or resisting it depending on the context is part of this negotiation.

5.2 Background: Dementia and Stigma

As noted in the previous chapter, the recent focus in the dementia care discourse created by the human rights, citizenship and social health approach to people with dementia as being individuals with potential to contribute to society (Bartlett and O'Connor 2007; Bartlett 2016; de Vugt and Dröes 2017; Dröes et al. 2017) has problematised the notion of people with dementia as being ill/ patients and consequently lacking capacities and abilities. Like most health conditions, dementia is widely recognised as carrying a stigma (Harman and Clare 2006; Milne 2010; Birt et al. 2017). The stigma can be viewed as a barrier to applying the perspective of people with dementia as having potential and abilities to contribute to society (de Vugt and Dröes 2017; Dröes et al. 2017).

In policy it has been emphasised that awareness has to be raised and stigma challenged in order to improve the wellbeing of people with dementia (Milne 2010). This policy has been developed in line with the topic of most studies on stigma connected to dementia which have been conducted so far. These studies have mainly focussed on developing a measure of stigma and its influence on carer burden and wellbeing of the person with dementia, informal carers and family members (Werner et al. 2011). How exactly does stigma influence the wellbeing of people?

Stigma as defined by Goffman (1963: 3) is an ‘attribute that is deeply discrediting’ and that reduces the bearer ‘from a whole and usual person to a tainted, discounted one’. When a stigma is attached to an identity perceptions and expectations about that person are altered and often lowered. As a result of these changes in view created by stigma, people are often viewed as ‘the other’. This classical definition is applicable in the context of dementia, as the stigma creates a view of people with dementia as ‘abnormal’ or at least as presenting ‘abnormal’ behaviour.

Ballanger (2006) describes how people in the US draw a distinction between normal and abnormal citizens when confronted with dementia. People with dementia would be placed in the ‘abnormal’ category. This categorisation is widely used in society; even GPs use it (Gove et al. 2017). In a study by Harman and Clare (2006), people with dementia say they experience this categorisation used by others in society and know they are viewed as ‘others’.

Dementia carries a stigma which implies that the people with dementia do not know what they are doing anymore. Although this stigma leads to an under-estimation of people's potential and abilities, it also provides a label that offers people with dementia the opportunity to deny responsibility for possible abnormal, discredited and or shameful behaviour. In a study by (Smith 2006) a couple of participants were disappointed when their symptoms were not diagnosed as dementia. They perceived a diagnosis of dementia as a possible tool to cope with the responsibility society ascribes to them for possibly 'immoral' and or 'troublesome' behaviour. Disclosing the diagnosis can help to reduce stigma and create agency (Birt et al. 2017).

Beard (2016) shows in her ethnographic research in a memory clinic how people who are diagnosed with dementia daily negotiate their identity of being a 'competent' person. But on the other hand, they identify with having dementia to provide an explanation for changes in themselves. Just like the participants in Smith's (2006) study, the participants in Beard's study accept the diagnosis sometimes to normalise awkward behaviour and provide an explanation that does not hold them personally accountable. But placing the responsibility for behaviour outside of oneself also reinforces the stereotype that someone with dementia does not know what he or she does, thus is incompetent.

Although stigma is attached to categorisations of moral/immoral and normal/abnormal, this categorisation is not static in daily life. In certain contexts, behaviour might be viewed as abnormal or immoral while in other contexts it is acceptable or even normal behaviour, as was illustrated by the example of Sue's incontinence in the previous chapter. Just as the stigma is context bound, people with dementia will sometimes disclose and accept having dementia while in other contexts they might prefer to deny or hide their diagnosis (MacQuarrie 2005; Preston et al. 2007).

Disclosing the diagnosis can sometimes be empowering and reduce the stigma as noted by Smith (2006), but hiding deviant behaviour can also increase the stigma (Birt et al. 2017). When a stigma is experienced in a certain context and people choose to deny or reject their diagnosis it can influence their access to services and support (de Vugt and Dröes 2017; Dröes et al. 2017) and their willingness to receive information on dementia (Harman and Clare 2006; Bunn et al.

2012). In this way stigma has implications not only for someone's identity and mental health but also for their broader wellbeing.

Sometimes people will deny dementia and instead normalise their symptoms, ascribing them to ageing (Clare 2002; Bunn et al. 2012). And/or they normalise their dementia by adapting their daily routine to the symptoms and continue to do what they used to do (Harman and Clare 2006). The creation of continuity in the daily routine not only establishes continuity in the practical experience of daily living but also creates continuity in identity and stigma management.

5.3 Coping with the Stigma of Dementia

5.3.1 'Yeah. I Never Mention That to Her. "No, No!" She Will Just Say, "I Have not Got That"'

In the opening scene of this chapter Bob explains why he does not tell Sue she has dementia. Sue denies the dementia, and if Bob mentions it, it will only create tension and hurt. Although Sue received a medical diagnosis, she denies it and Bob resists the diagnosis to avoid upset and conflict with Sue. This resistance influences their opinion and access to help and support. Their son had encouraged Bob to apply for some support and a social worker had visited them but Bob was not too happy with the situation.

The social worker had suggested Sue could attend a day centre or activity group at least once a week, to give Bob a break. Sue used to play bingo in the local community centre, but since it had closed she could not go there anymore. The social worker had offered to put them into contact with someone from a local charity who could join Sue at a couple of day centres or activity groups so she could try them out and decide which ones she liked. Bob, Sue and I talked about the social worker's idea; I asked: *'What do you not like about that idea, Sue?'* '*Is it because you do not know the person, maybe?' 'Mmm, I like to…'* Sue does not seem to be able to find the right word to answer, so Bob chips in as if he knows what Sue would like to say: *'And the woman, she says it is possible she might take you for a walk or you might go on bus to go shopping. She did not say you would have to stop at the community centre all time'. 'I did not say I am stopping here all time',* Sue replies. *'I did not say...'*, Bob starts, and Sue interrupts him; '*You want me to'.* I try to calm down the conversation and clear up the misunderstanding: *'No. I do not think so.*

Shall we, shall we, shall we...' While I am trying to change the topic Bob interrupts me: *'It will occupy your mind, Sue'. 'My mind is alright*', she replies.

Sue takes the cup that holds her pills in her hand and plays with it. *'Do you need some water to take them?'* I ask her. Bob stands up to get her a glass of water and says *'Have you not taken them yet? I gave them to you this morning'*. There are four pills: a big one, a smaller one and two little ones. *'Sometimes she does not want to take them and throws them away',* Bob continues and he hands Sue the glass of water. She takes the big pill and puts it in her mouth while she holds the little pills in her hand. She walks to the sink, spits out the big pill and all the water, throws the other pills in the sink and lets the water run. Bob stands up and says*; 'Where are the little pills, open your hand, what are you doing? You have to take those!' 'You cannot tell me what to do',* Sue shouts at him. This makes Bob want to shout back; he raises his voice for a second and then quickly lowers it again, walks back to the table and tells me: *'She will not listen anyway'. 'You always want to tell me what to do! I do not want you to tell me what to do!',* Sue continues. *'Why do you not want to take the pills?',* I ask Sue. *'I am normal'*, she replies.

Sue knows that someone would have to come to the house to take her to these activities because they think she cannot do it on her own anymore because she is ill; she has dementia. Sue does not feel ill and does not want to be pushed into going to activities especially for people with dementia. Sue likes to keep doing things the way she wants to, when she wants to. She does not want to accept any help, support or medication. Eventually she accepted going to a day centre with a volunteer once but refused every other time. When Sue refuses help it also means that Bob will not get the support he needs.

Bob respects Sue's wishes and also becomes sceptical about accepting help; furthermore, he asks me to avoid using the word dementia around Sue. One afternoon when I join them to visit their cousin Ben, he asks me how I met Bob and Sue. I am just about to tell him we met at a dementia support group, as we did, but Bob quickly chips in; *'We met at a neighbourhood watch meeting'. 'Really?'*, Ben comments*. 'Yes, I visited different community groups to meet elderly who would like to take part in my study',* I back up Bob.

5.3.2 'I Never Mention She Has Dementia to Her, I Just Call it Memory Loss'

Dan also likes to avoid the use of the word dementia although Mary has a diagnosis.

Both Dan and Mary like to frame it as a symptom of getting older:

'You know, as you get older, you know what you think, oh I cannot do that, it is too much for me. Something tells you that you can but then there are other times when you think, oh I cannot really do it, but Iwill do my best, you know', Mary explains. *'How does it feel to have to accept that you cannot do certain things anymore?',* I ask. *'Well you just find as you get older that it is just too much for you',* Mary replies. *'Yeah, you get to a point where you accept it, that you cannot do what you used to do. We always used to go hiking with a group of friends. We would be out there for five or six hours, but nowadays we know very well we cannot do that anymore. So, we have got to adjust life to what we are able to do. I find, if I had been in the garden or if I go to the exercise class, in the afternoon like I do, I do not have energy any more later on. I might want to do something else but I do not feel capable of doing it',* says Dan supporting Mary's view. *'It is too much for you when you get to a certain age, if you have been doing other things. And you think, oh gosh I am tired. You know, when you were younger that did not bother you',* Mary continues.

Framing the dementia and co-morbidities as part of the loss of abilities that comes with growing older makes it possible for Dan and Mary to identify with others of their age, Dan explains: *'Discussing health is a fairly big topic of conversation among older people is not it, you know. I have got an ache and pain here, or one, something like that. Or have been to the doctor for this, or, and… Not the only conversation by any means, but invariably it does arise during the course. They are all in the same boat…usually'.*

5.3.3 'I Have Got Rid of the Dementia, I Only Have Some Other Health Conditions'

John explains to me when I ask him about his dementia. Although his wife Diane accepts the diagnosis, she explains how she does not always wish to identify with being a couple of whom one partner has dementia. She explains how she likes to go out with John but it is not always easy because of his dementia and people's response to it and or John's specific needs. Sometimes it is easier to go out with other couples of whom one partner has dementia but sometimes Diane prefers to be around people who are not:

'Although, I think he enjoys being out, there are aspects where we are with people

that are not fellow travellers on the path I am on, it is not easy to always deal with it. At the moment, I am far more comfortable with people who are dealing with it, than… I do not, this is going to sound awful, I do not always want to be with people who are dealing with it though. I sometimes want to be with people that are not, so I do not have to talk about it'.

It becomes clear how she sometimes prefers to be around other people with dementia and their carers because they will understand better how to interact with John and will accept his behaviour when others might classify it as 'abnormal' and 'immoral'. Other times she does not like to be around people whose lives are similar to theirs as it facilitates talking about dementia and she does not always want to talk about it.

5.3.4 'I Do Not Have Any Big Problem, but Dementia'

'Dementia is nothing. Dementia, if I laugh, if you laugh; ha ha ha ha ha ha ha ha, if you laugh like that, dementia goes away. Dementia, dementia is not a very hard thing', Hamid continues. I ask him: *'Do you think the dementia goes away? Or does it just make you feel better when you laugh about it?' 'Yes, that is right, that state finishes',* says Hamid. *'No, it is very difficult, not easy, it is a very hard thing this one, it is a memory problem and brain problem, the brain does not do anything',* Aaisha contradicts him.

Hamid explains to me that he does not experience living with dementia as difficult. According to him it comes and goes and he can control this state. He might sometimes be more aware of the dementia than other moments. His wife Aaisha experiences her husband's dementia differently. She does find it a difficulty and does not agree with Hamid that it is just a temporary state. Hamid identifies with having dementia sometimes while Aaisha seems to accept Hamid's dementia diagnosis all the time.

5.3.5 'You Know, 'Because Alan Has Good Days and Bad Days and Is Somebody Who is Very Confused'

Jane explains that Alan has dementia and that this means he is very confused. Alan confirms this; '*I do get confused, I do not know what, when I wake up and I do not know what day it is'.* Jane used to be a volunteer in the hospital and recognised the

signs of dementia early. Alan accepts the diagnosis and describes some of the symptoms he experiences, such as the confusion. In this case both spouses accept the dementia diagnosis.

5.4 Accepting Dementia

Every couple in my project makes sense of the dementia differently and negotiates when to identify with the diagnosis. Only Jane and Alan both accept the diagnosis. In all other couples there is more resistance, mostly by the person who has dementia. All of them want to be 'normal', but dementia seems to set them apart as being 'abnormal', so they do not want to have it.

This creation of a category of 'abnormal' might be influenced by the negative views on dementia represented in the media as mentioned in the introduction: 'Dementia is the Leading Killer of Women', 'Dementia is the Biggest Killer for Women' and 'Alzheimer and Dementia are Second Biggest Killer in Australia' (Davey, 2015; Hope, 2014; Sabin, 2014). Lock (2013:1) emphasises the influence of negative media coverage by speaking about how society nowadays labels Alzheimer's disease as a new pandemic, an epidemic disease. She notes that a quick run on google with the search term dementia will give you hits of titles such as 'Alzheimer's Disease: A Global Epidemic', 'Alzheimer's "Epidemic" Hitting Minorities Hardest' and 'Alzheimer's Epidemic Will Follow the Obesity One'.

Another possible influence on why people do not always want to accept the diagnosis might be the realisation that a diagnosis brings a certain identity and 'special' treatment. As shown in the vignette of Bob and Sue, Sue does not want to go to activities especially for people with dementia, nor does she want to take medication. She conceives of herself as 'normal', and normal people do not go to these places or take medication. Diane explains how sometimes this 'special' treatment and understanding is helpful but other times she does not want to be confronted with the diagnosis of her husband and all its implications. Sometimes, she prefers to be around people who are not dealing with it.

Dan and Mary frame dementia as part of ageing, identifying cognitive impairment as part of the loss of abilities that every ageing person will experience. They are able to 'normalise' the dementia and identify with others in their age group (Botsford et al. 2012). Approaching the symptoms as part of the physical changes of ageing enables them talk about some of the challenges and symptoms with friends

who are also ageing as if it is a normal, widely shared challenge.

All of the people with dementia in my study also had co-morbidities; while most of them had difficulty accepting the dementia diagnosis none of them denied any of their other health conditions, including diabetes, heart problems and mobility problems. Different illnesses influence identity differently (Becker 1997). It does have to be stated that all of them had developed the co-morbidities before they developed the dementia. In this sense dementia was the diagnosis that was most likely to set them apart from their peers and cause them to be viewed differently.

The development of health conditions and loss of abilities is connected to ageing anyway. Accepting the diagnosis does not seem to be a definite acceptance or rejection, but more a negotiation of identities. In some situations and contexts, the couples are willing to accept the diagnosis and the attached identity of demented person or carer and in other situations they resist the diagnosis. Sometimes people like to be normal while other times they need to accept being different (Becker 1997).

How comfortable or uncomfortable the couples feel with accepting the diagnosis in different contexts depends on the stigma and implications a diagnosis carries in these contexts. This can be connected to identity theory, as I will explain in the next chapter. As already shown in Sue's resistance to her diagnosis, the acceptance of the diagnosis impacts on the access to health and support services for the couple.

5.5 Access to Support Services and Health Care

As mentioned in the background of this chapter, the experience of a stigma can influence the access to health care and services (de Vugt and Dröes 2017; Dröes et al. 2017). In this section I would like to reflect on this phenomenon by drawing upon some examples from my data that show how the stigma experienced by the couples influenced the way they accessed care, help and support.

Although all couples had obtained an official dementia diagnosis at a memory clinic, which implies that they had access to formal health care and support services, their acceptance of the diagnosis influenced their access to actual care and services. As shown in the previous part of the chapter, Sue's rejection of the diagnosis impacts on the couple's access to health care and services; Bob cannot access respite care as Sue will not accept going to a day centre or support group or even

accept the company of a volunteer joining her on activities she likes to do.

In other cases, the couples do access health care and support, but their resistance to accepting the diagnosis might create a barrier to receiving the right information and/or building up the skill needed to care for someone with dementia. Dan and Mary's framing of dementia as just another part of ageing does not prevent them from going to medical appointments or attending support/activity groups; they have appointments at the memory clinic, Mary goes to a day centre twice a week, a sitter comes to their house one afternoon a week to do activities with Mary and they attend two dementia activity groups. Still, they do not seem to receive valuable information about dementia.

Dan found it increasingly hard to cope with the symptoms of dementia especially Mary's confusion about wanting to go home or visiting her mum, which will be described in more detail in Chapter 6. Even though they access all these services, Dan did not know how to cope with this confusion. Eventually he decided to contact another charity and received the information needed to understand the confusion; he commented, *'These leaflets I got from the dementia people certainly fit exactly how Mary is'*.

We need to ask ourselves how people can seem to have access to information and professional and peer support on dementia and care but not seem to receive the appropriate information and/or build up their skills. Does this have to do with the way the information is provided and/or contact with 'patients' and 'service users' is organised? I once had a conversation with Dan in which he described his experience with the memory clinic:

Denise *'So you do not see the same person at the memory clinic, but, well, does the person you see know about other health issues you may have?'*

Dan *'Not really, I do not think so, unless, I do not know what records they have access to. I think she could possibly pick up the doctor's records on the computer and look at anything she wants to know there. But she does not seem to concern herself with that'.*

Denise *'Do you think that it would be more helpful if she would?*'

Dan *'I would have thought so, yeah. Because I think your general health – you*

have got to take your life in general, what you are doing in the day. One thing affects another sometimes, does it not?'

Denise *'Do you only talk with her about the pills that you take or also about other issues?'*

Dan *'Not really, no. She just asks how we are keeping, and one thing and another. You know the opinion I get is that there is not a lot they can do apart from the pills, and as long as they are not creating a problem, that is okay'.*

Denise *'Okay, so, at the memory clinic they do not inform you about any support services that are available in the area?'*

Dan *'No, they have not done that at the moment, no. It is just a matter of saying, are the tablets making you ill? Or do you think they are doing any good?'*

Do the memory clinics only provide information on medication? According to the website of the local NHS Foundation Trust (NHS and Trust 2018), their memory service does provide support and information on how to live well with dementia. We could question how much of this information is tailored to the individual and takes into consideration the local landscape of support groups, activity groups and services. Dan's account fits within the biomedical model of somatic medicine (Kaufman 1994). The health care professional at the memory clinic focuses only on the symptoms of the dementia and the medications which could offer some improvement, while he seems to want to have more holistic support that takes into consideration their daily life activities.

But he also did not receive the information at the dementia activity groups, which they accessed not through the recommendation of the memory clinic, but because their neighbours organised the singing group and asked them to join. How come they did not receive information about the care for someone with dementia at the activity groups? The Alzheimer's Society (2017) does state on their website that activity groups aim to offer a space to relax while doing an activity you enjoy and to create a place where you can talk both to others in similar situations and to professionals about other questions you might have about dementia and its care. In this way, these groups are a possible source of information, but it has to be

accessed by the participant on his or her initiative.

Dan and Mary mainly enjoyed these groups to be involved in an activity together, not as a source of information on dementia care. One of the reasons for their not asking these types of questions at the groups they attended could be the stigma that is attached to having dementia: avoiding the diagnosis and not wanting to talk about it at these groups.

Photo 11A Dan & Mary enjoy the music at the local wellbeing café[26]

While these groups did not provide a source of valuable information for Dan and Mary, similar groups did provide such support for John and Diane. Diane emphasises the fact that these groups provide her with a safe space in which experiences can be shared: *'We can have everything in between that in the whole session. But it all stays behind the door'. 'You might say something you feel for example about the way you love people, and somebody else can say, oh, yeah, I feel like that, and you realise...' 'No judgement, no judgement and you realise you are not on your own'. And the groups are quite relaxing, it is also about feeling that nobody will be surprised what happens'.*

[26] Participants approved of publication

Photo 12A Diane 'Relaxing at the dementia support group'[27][28]

Although these groups do provide Diane with peer support, advice and information, it becomes clear that she experiences a stigma and only feels able to talk about certain aspects of caring for her husband with dementia in a 'safe space': behind closed doors and among people who do not judge her. She knows she might have feelings and or experiences in life that can be viewed as 'abnormal' by the majority of society. This makes apparent that these couples experience stigma, taboo and judgement for which they try to find a coping strategy, so they do not have to face this stigma, taboo and judgement all the time. Negotiating their identity of having dementia or being a carer in different contexts helps them to avoid being confronted with the stigma, taboo and judgement in some contexts. The difficulty is that resisting the diagnosis in some contexts impacts on accessing support, information and care that might actually be much needed.

In which contexts one accepts or rejects the diagnosis of dementia can impact on the disruption and continuity in daily life. Accepting the diagnosis can create disruption as it might entail starting certain activities that the person never used to do: attending a day centre, having a volunteer joining on daily life activities, having to take new medications and attending dementia-specific medical appointments. Sue, for example, does not want any of these things; rejecting the diagnosis gives her the space to keep doing what she wants to do, when she wants to do it and preferably on her own. In contrast, accepting the dementia diagnosis could give Bob some

[27] Description of picture provided by the couple in their photo diary.
[28] Participants approved of publication

space to continue to do certain activities he always used to do on his own, like going to the pub on Friday, while someone else stayed with Sue.

On the other hand, attending support and activity groups together provides Dan, Mary, Diane, John, Jane and Alan with new shared activities that they enjoy doing together, creating a means for continuity in sharing their daily lives together. Accepting the diagnosis could offer access to help and support that can help the couples to sustain and/or create a new continuity in their daily life while it also creates disruptions by providing new activities and routines that may disrupt existing ones.

Not only does the stigma and acceptance or rejection of the dementia diagnosis influence the current continuity in the daily routine, it also shapes the perspectives couples have about the future, as explained in the systematic synthesis of the spouse care literature in Chapter 2.

5.6 Anticipating the Future

Bergman et al. (2016), Daniels (2007), Walters et al. (2010) and Sinclair et al. (2018) explain that how people make sense of their dementia and co-morbidities does not only influence people's perceptions of their daily life but also their perceptions about their future daily lives. The dementia creates a confrontation with changes in the perception of the past, present and their future together. They especially highlight how perceptions of the future change under the influence of anxiety. Walters et al. (Walters et al. 2010) show how the future becomes more unpredictable as couples can no longer make future plans together.

I will now show how the perception of the future of couples in my study was connected to their acceptance or rejection of the dementia diagnosis and its consequences on in their perceptions of the future. These perceptions of the future could be viewed as part of the process of continuity and disruption as explained in the previous chapter.

5.6.1 Jane and Alan

'It would be handy to have them back on across there because sometimes in the winter you get a draft coming in through the kitchen. And it would make this a bit smaller and cosier', Alan says to Jane about the doors in the living room. *'Well that*

is something to think about, love', Jane comments. *'That is for next year now',* Alan concludes. Alan talks about next year as if nothing will change, but actually his health is rapidly deteriorating. Although as noted earlier in the chapter Alan accepts his dementia diagnosis, when he speaks about the future he seems to ignore the possible consequences of the progression of his dementia and co-morbidities. A couple of weeks after this conversation, the GP put him on a palliative care pathway. Jane, on the other hand, does accept the future implications of dementia: *'Our daughter thought about getting a granny flat attached to their house. But of course, now change is not a good idea at all at the moment'.*

Both of them talk about the future to create some continuity in their daily lives, by either having the perception that it will not change much or by anticipating the possible changes and thus avoiding moving house. While Alan avoids including his dementia and other health conditions in his future perceptions, Jane centres her perception around these consequences.

5.6.2 Diane and John

'Because when I had a blow out, where I, I just went, I cannot do this, and it was, I, I did that on the Monday and he was in care on the Tuesday for a week. And at that point, the home that he was in managed him really well'. Diane pauses for a minute, then she continues; '*And, because you know, he does not do homes?' 'Yes, you told me',* I confirm. '*The social worker said, he has settled, why not leave him? And I thought, I cannot, I just cannot do that. And basically, maybe I should have done',* she reflects.

Diane knows that the care would become too much in the future. She has already sent John into respite care, but leaving him in a home would be a very difficult transition for her which she resists. On the one hand, she is worried that John will not settle in, as she told me about times in the past when he went into respite care and tried to leave the homes, either by repeatedly opening emergency doors or even by climbing over the fence at the home. Also, she does not think she is ready for this change; not sharing a home with her husband would cause a major disruption in their daily routine for which she is not ready.

The future scenario of her husband moving into care would create a disruption in her daily life experience; by resisting the transition as long as possible she creates continuity between the present and future. In this context of making plans for the

future, she decides to avoid accepting the consequences of the dementia.

5.6.3 Dan and Mary

'My big worry now is that there is no way Mary could manage on her own if anything happened to me. No way! So, we went to view another home'. He reasoned from the perspective of his not being able to care for Mary anymore and made arrangements to be put on a waiting list. Dan and Mary liked to plan ahead in life, it was part of their ethos: *'Knowing that. I mean, we have worked all our life, we have saved as we have gone along, that is our way of doing it, we wanted a nice home, and to be able to maintain ourselves in old age, which we can do. I cannot really ask for more than that'.* Dan created some continuity in this future transition/disruption by connecting it to one of the main values he lived by throughout his life. Although usually he resists Mary's dementia diagnosis by framing it as part of ageing, he is willing to accept the diagnosis in his perceptions of the future.

5.6.4 Bob and Sue

'Have you got anything in place for when the situation of your wife changes?', I ask Bob. '*No, not yet. We have – she came in Friday, social woman. She had been trying to get in touch with me for a fortnight',* he replies. On another occasion Sue had said: *'I do not want to move into a care home'.* Bob added, *'People are finished within six months once they move into a care home'.*

Bob and Sue prefer not to think about the future perspectives as they worry that a move into care would mean the end of their life in their opinion. Moving into care would cause a major disruption of their daily life. Still, a social worker has contacted Bob to discuss future options. By avoiding thinking about or taking the initiative to act upon the future Bob and Sue resist the dementia diagnosis and its consequences, creating continuity in their daily life.

5.6.5 Aaisha and Hamid

'Our oldest son asked us to live with them, he built us a room and bathroom at his house, he told us to sell our furniture and move in with them. I would like to move to a smaller house for me and Hamid keeping our own things but I do not want to move in with my son and daughter-in-law. Our children do not want us to move to a smaller house, so I told them we are staying in the house we are living now. I like the

location of our house – it is close to the mosque, the shops and the centre of town and we know the people in the neighbourhood', Aaisha explains when I ask her about future plans.

She likes to continue caring for Hamid herself and does not seem to think too much about the progression of the dementia and when it will become too difficult to keep caring. She creates continuity in the daily life experience by continuing to care at home. She resists the consequences of the progression of the dementia in her future perspective.

Some couples seem to accept the diagnosis and its implications when talking about future care arrangements, while others tend to ignore it. What all couples do is try to create some continuity between their current life and the future while planning possible transitions or resisting them for the same reason.

5.7 Summary

'Dementia is the Leading Killer of Women'; 'Dementia is the Biggest Killer for Women'; 'Alzheimer's and Dementia are Second Biggest Killer in Australia' (Davey, 2015; Hope, 2014; Sabin, 2014) These negative titles in newspapers still represent a stigma and anxiety about dementia which is daily experienced by the people with dementia and their partners. It influences how they make sense of their health conditions and cope with disruption to create continuity in daily life. The identity of 'demented' person sets them apart from peers without this label as being people who act 'abnormal', lose abilities and need to go to specially organised activities and be looked after all the time. All people with dementia and the caring spouses try to negotiate in which contexts they are willing to accept the identity and stigma connected to having dementia or caring for someone with dementia and in which contexts they reject or avoid it. How they negotiate these identities impacts on their access and acceptance of services and health, shapes future expectations and anxieties and helps them to create continuity in their daily lives. How they negotiate identities is influenced by their habitus and selfhood. I will explore this in more detail in the next chapter where I will discuss how these identities are embodied in their daily lives and influence the relationship of the couple and their daily life routines.

Chapter 6

‘I Can Deal with That, Better than I Do with the Wife Thing’:

Selfhood, Identity, Dementia and Co-morbidities

‘It is, it is interesting, I was talking to somebody whose husband got early onset. She is younger than me and he died three days ago. She said something that I think, but did not dare to say, which is that you still love them, but not in the same way. Not in a wife way, it is in a carer way, and that is dead hard to admit but we all feel like that. I thought, oh thank God for that, it is not just me being a bitch’. She continues: *‘I think it – it does stop being a marriage after a time, it becomes a care situation, and, in some ways, I can deal with that, better than I do with the wife thing’.*

6.1 Introduction

In the comment above Diane reflects on how she must negotiate her identity as a ‘carer’ and wife and how this has influenced the way she loves her husband. Identifying as a ‘carer’ and admitting that she loves her husband differently was difficult for Diane, and she experienced judgement from others for having these feelings.

As discussed in the last chapter, identities connected to living with and caring for someone with dementia hold a stigma connected to being ill, being incapable or being a carer. These identities challenge other identities that the individuals hold including their identity of being a husband or wife. As shown in Chapter 2, according to existing literature on spouse care, couples of whom one has dementia and the partner is the carer go through a process of redefining their relationship, moving through different phases of sustaining couplehood, maintaining involvement and finally moving on, after which they decide to continue as ‘we’ or ‘I’ (Hellström et al. 2007; Walters et al. 2010; Beard et al. 2012; Botsford et al. 2012). Identities play an important role in this redefinition process as they can create both continuity and disruption in the relationship of the couple.

In this chapter I show that this process is not necessarily a linear process and that different phases like ‘we’ and ‘I’ can co-exist. Identities are plural and how the couples decide which identities to act upon, in which situation of their daily life can be better understood by using the dialectic relationship between the habitus, body,

common sense and environment as described by Bourdieu (1977; 1990) and the identity theory described by Burke and Stets (2009). I will especially pay attention to explaining how the adaption of a certain identity can become difficult when cognitive impairment and co-morbidities challenge the function of the habitus and body in the dialectic relationship and how this can create challenge in daily life for the couples. I will focus on how the changes in habitus in relationship with the environment, common sense and body impact on the sense of being at home, the relationship between the couple and the couple's strategies for coping with the dementia and co-morbidities.

First, I will give a short summary of some of the major developments in the selfhood discourse within dementia care and discuss how the discourse could be developed further by focussing on the process in which a selfhood is created, including a further exploration of the concept of 'embodied selfhood' as developed by Kontos (2004; Kontos 2006). Secondly, I will introduce identity theory by Burke and Stets (2009). Thirdly, I will discuss how identity theory and the dialectic relationship of Bourdieu can strengthen each other to build a useful framework for selfhood in the context of daily life with dementia and co-morbidity for couples in the community. After this theoretical exploration I will show how this framework can help to understand the challenges of the couples described in my data better.

6.2 Background: Selfhood and Dementia

Dementia is often associated with the loss of selfhood; in the past people with dementia have even been portrayed as being the living dead (Small et al. 2007). Especially the cognitive impairment created by dementia has been viewed as an illustration of the loss of the self (Hughes et al. 2006; Lesser 2006). This perception is rooted in the idea that our present identity is connected to our past identity through memories. This idea was constructed in the Western philosophical tradition by, among others, John Locke, who theorised that we are who we remember ourselves to be (Warburton 2011); following his theory we would lose our selfhood when we lose our memory function. In the selfhood discourse within dementia care this perception has been challenged through two main discourses: the selfhood and humanity discourse and the embodied selfhood discourse.

In the 1990s Kitwood introduced person-centred care for people with dementia, in which he emphasised the importance of acknowledging these people's

humanity, needs and wellbeing. He stated that people with dementia cannot lose their selfhood as they are humans with feelings who can show and feel emotions (Kitwood and Bredin 1992). Sabat (2001) followed this line of thought and described selfhood as consisting of three components: firstly, the personal identity, which he describes as an expression of the person's emotions and interaction with the surroundings; secondly, the physical and mental characteristics, such as height, the activities the person likes to do and the person's norms, values and interests; thirdly, the social identity, which is established in social interaction.

He and Kitwood argued that the social identity can be sustained by others who interact with the person with dementia, acknowledging that person's social identity (Kitwood and Bredin 1992; Sabat 2001). Although the interactions of the person with dementia with their surroundings based on feelings and emotions shows some ability to express their own selfhood, the idea of sustaining selfhood was mainly based on how others interacted with the person with dementia. This view portrayed people with dementia as mainly passive actors whose identity others had to sustain.

The embodied selfhood discourse challenged this perception, showing how cognitive impairment does not disable people from embodying their identity and making them active actors who can communicate their own identity. Kontos (2004; 2005; 2006) uses this principle to show how people who are living with dementia do not lose their selfhood. Using descriptions from her fieldwork in a Canadian nursing home, she showed that people with dementia still hold on to a certain 'lifestyle' by the way they dress and behave. One description she gives is of Molly, a resident from a higher social class: 'the concordance between Molly's silk blouses and pure white pearls, her small and delicate steps, and the polite manner in which she wiped the tip of her nose' (Kontos 2005: 563). She argues that the cognitive impairment does not prevent the residents from expressing their selfhood. She also gives the example of Ethel, a woman living with dementia who can still stitch although she does not remember she did it before and even tells the women from the creative activity that she cannot stitch. But as soon as the woman gives her a canvas, a needle and some yarn, she starts stitching like she has done it often before. She behaves in an subconscious manner like the 'motor response' or 'sense pratique'.

By showing how selfhood is embodied by drawing upon Bourdieu (1977; 1990) and Marleau Ponty (1962), Kontos (2004; 2005; 2006) has taken a first step in

exploring how the selfhood of people with dementia is embodied through an interplay of the habitus with the common sense and environment. Although she shows that the loss of cognitive abilities does not prevent the body from communicating its embodied selfhood, she does not discuss in depth how dementia and health conditions might impact on the way the body embodies this selfhood. She even concludes the following: 'Despite their severe cognitive impairment, the residents were not launching their bodies into blind attempts to perform an action. The movements of their bodies were perfectly suited to the circumstances (Kontos 2005:561)'.

Furthermore, she does not discuss possible changes in the habitus and the broader impact of changes in the dialectic relationship between the habitus, the body, common sense and environment on the outcome of this relationship and the person's position in social context. In this chapter I will show how these changes can impact on the embodiment of the selfhood and create behaviour that is not always suited to the circumstances drawing up on examples from my fieldwork.

The debate so far has been focussing on whether there is a loss of selfhood and how we can counter the perception of loss by taking into consideration embodiment (Kontos 2004; Kontos 2005; Kontos 2006; Kontos 2011) and/or by actively sustaining the social and personal identity of someone by acknowledging their feelings, emotions and interaction with the environment and others and by actively creating an environment and a type of social interaction that sustains their selfhood (Kitwood and Bredin 1992; Sabat 2001). Even though we have paid attention to how identity is created in social interaction, we have mostly focussed on recognising the selfhood/identity of the person with dementia. However, identity and selfhood are based on mutual recognition (Oppenheimer 2006; Radden and Fordye 2006). An interaction that is not based on mutual recognition of identity can be upsetting for the person whose identity and selfhood is not acknowledged (Radden and Fordye 2006). For example, it can be upsetting for the caring spouse not to be acknowledged as spouse while he or she does still acknowledge the partner with dementia as his or her spouse.

So far, the selfhood discourse has mainly been developed around the question of whether dementia creates a loss of selfhood. This focus is problematic because it asks for a confirmation or rejection of the loss but has not fostered an exploration of the dynamic process in which selfhood is a constantly evolving thing. It

would be better to talk about the change of selfhood (Radden and Fordye 2006; Caddell and Clare 2010), acknowledging its evolving nature

Furthermore, the selfhood discourse so far has not paid enough attention to the multiple identities people with dementia hold and how they influence their positions in society (Bartlett and O'Connor 2010). Sabat (2001) paid attention to personal and social identity which showed awareness of the plurality of identity of people with dementia but he did not discuss in depth the connection of this plurality of identity to the different positions people with dementia hold in society. Bartlett and O'Conner (2010:42) suggest that identity is an inadequate concept to fully capture people's position in society. They suggest the use of the concept social position. In this and the next chapter I will show how Bourdieu's theory of practice in combination with identity theory can offer a perspective in which identity and social position are connected. In this chapter I will mainly discuss the influence of dementia and co-morbidities on identity of the person with dementia, their spouse's identity and their relationship. In the next chapter I will use the identity perspective introduced in this chapter to show the connection between both spouses' identities, positions and roles in their social networks and the community by discussing their involvement in these social realities.

If we would like to understand the evolving nature of selfhood, its connection to social positions in society and how it can be perceived as lost by others in social situations we need to understand how selfhood is constructed through the interaction of the person in different contexts. I will now introduce the theoretical framework that can enable us to create this understanding, starting with a discussion of identity theory.

6.3 Identity Theory

As mentioned in Chapter 3, identity theory can counter some of the limitations of Bourdieu's theory of practice. The limitations of the theory of practice were that it fails to clarify well the individual's experience, and that it fails to take into account how people engage in different fields, that it does not pay enough attention to intersectionality and that it does not explain well enough the role of social networks. Identity theory does acknowledge that people interact in multiple contexts daily and that how they behave and who they are is context dependent. I will now explain the

identity theory I used in the thesis and make clear how it helps to overcome the limitations of Bourdieu's theory of practice.

'An identity is the set of meaning that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person' (Burke and Stets 2009: 3). Every person has multiple identities, everyone is a member of multiple groups and plays multiple roles in society. For example, someone can be a mother, a daughter, a woman, a nurse and a wife all at the same time. Those identities exist only in the context of social structure (Burke and Stets 2009).

The identity people are identifying with shapes the way they interact with each other; for example, the way spouses interact with each other often differs from how they interact with their children. We need to recognise each other's identities in order to interact accordingly. This recognition is based on awareness of expected behaviour and embodied symbolism shared in the environment originating in our common sense and cultural framework (Burke and Stets 2009). Identity theory looks at the individual level and acknowledges the multiple identities someone holds, the different contexts in which someone interacts and the role of others in the recognition of identity. In this way, identity theory offers an opportunity to overcome the limitations of Bourdieu's theory of practice.

Another element of identity theory is the environment, which plays a key role in the interaction between people as it can carry the symbolism needed to clarify each other's identities (Burke and Stets 2009). Objects can carry part of our identity, by reminding us of a social identity (Hughes et al. 2006; Erol et al. 2015). Bourdieu states that our habitus is embodied and represented in the way we design our environment, like the kind of furniture we put in our house (Saunders and Williams 1988; Goodall 1990) Who we are is influenced by our being in the world and by the objects around us (Hughes et al. 2006).The influence we have on 'designing' part of our environment gives us a tool to influence our identity communication and negotiation.

An important part of this negotiation of identity is the power relationship of the people with whom you interact; an identity can give someone power and power can influence the identity you can adopt. The differences in power positions and cultural frameworks that people hold can create a challenge in the mutual recognition of each other's position. The greater the consensus between the people involved in the

interaction, the more likely there will be a positive outcome of the identity negotiation process; the less the consensus, the more fluid and changing the outcomes of this process will be. Burke and Stats (2009) describe this negotiation as a process with different components, which fits well Bourdieu's dialectic relationship. In the next part I will present this framework and how Bourdieu and Burke and Sets could complement each other to build an analytical framework to look at selfhood in the context of spouse care.

6.4 Bourdieu's Dialectic Relationship and Identity Theory as a Tool to Understand the Redefinition Process of the Relationship

According to Bourdieu (1977; 1990), the way we live our lives and make sense of our world is the outcome of a dialectic relationship between our habitus, common sense, body and environment/field. The habitus consists of our ethos, the values and ideas which we adopt as part of our upbringing, and past experiences, all the things we have experienced so far. The body is the embodiment of the dialectic relationship; the way it behaves and looks is influenced by the habitus, common sense and the environment/field in which it finds itself.

According to Burke and Stets (2009), our identity works as a system. The output of the system is our behaviour or the role we play. The components of the system are an input, a standard, a comparator and an output. First, there is the **input:** which are someone's perceptions. Secondly there is **the standard:** a set of meanings that we ascribe to an identity, for example certain characteristics, like being caring. The standard compromises of our perceptions, the way we interpret our environment and the meaning we attach to situations. When we incorporate Bourdieu's ideas we could state that the standard and input will be based on our social habitus/common sense and our individual habitus.

Thirdly there is **the comparator:** which compares the identity standard with the person's perceptions just like the process of fitting the habitus within the common sense of people we interact with and the doxa of a field. Finally, there is **the output:** the way the person performs an identity/role, the embodiment of the outcome of the dialectic relationship of Bourdieu. When the identity standard and input match, the outcome will be positive: the person will perform the behaviour that matches the identity that person likes to adopt, and it will fit with the person's disposition and

expected role, within the environment in which the identity is negotiated. A positive verification of the identity like this will give the person self-esteem. A mismatch between the identity standard and perceptions will give an error and decrease the person's self-esteem, and a negative outcome makes people modify their behaviour and/or causes upset and distress. Similarly, the mismatch of someone's habitus, wherein their common sense or behaviour does not accord with their disposition, creates a clash. This process of identity verification is ongoing; people are constantly monitoring their environment for symbols and signs about which identity would be appropriate in that environment/situation. Perceptions are influenced by the environment, social structures and behaviour of others and our past behaviour, just like our habitus and common sense. The ongoing process of negotiating and recognition of identity can be interrupted when mis-recognition takes place.

Bourdieu's dialectic relationship gives a deeper understanding of the development of the 'input'/perceptions as both an individual and group process, as he explains well what the individual habitus is and how a common sense is created within a group. His theory also sees the body as playing a key role in communicating, recognising and negotiating identity.

On the other hand, identity theory presents a dynamic process of identity verification that can help us to understand how the concepts of the body and habitus in Bourdieu's theory of practice are changeable and dynamic as a result of the dialectic relationship within the identity verification process.

6.5 The Analytic Framework and Spouse Care Literature

As shown in the background chapter, the main finding within spouse care research is that couples go through a process of redefinition of their relationship when one partner develops dementia. Different developments are identified as triggering and influencing this process: changes in the person with dementia, changes in reciprocity, difficulty having conversations, inability to plan a shared future, changes in roles, accepting external support and differences in both spouses' involvement in activities (Jansson et al. 2001; Daniels et al. 2007; Hellström et al. 2007; Vikström et al. 2008; Walters et al. 2010; Beard et al. 2012; Botsford et al. 2012).

Although these changes and processes have been identified by many scholars in dementia care research, we have not spent much time analysing this

process and these challenges holistically. Such understanding would, for example, enable us to understand the influence of these changes and the process within a couple's relationship on their 'help and support' seeking behaviour, their support needs, and their access to support and care.

Taking into account the way the couples in my study experienced such challenges and were involved in a process of redefining their relationship, I would like to show how a focus on identity in these challenges and this process can help us to understand them better and link them to the important topics within dementia care: help-seeking behaviour, the influence of environment on care and the carer identity. First, I will discuss two examples of couples who are resisting the redefinition and how the loss of a common sense creates challenges to do so. Secondly, I will discuss how co-morbidities can make the embodiment of the habitus difficult and how this complicates the process of the redefining the couple's relationship. Thirdly I will show how the loss of shared memories and challenges in embodiment together challenge the common sense. Finally, I will discuss how a carer has accepted the redefinition of her relationship with her husband and how this creates a different interpretation of his embodiment, a sense of loss and a sense of shame by diverting from the common sense.

6.6 Resisting the Redefinition of the Relationship

6.6.1 Bob and Sue: 'I did not marry him. It is true, I am not joking, no. He does not like me telling you, but we were not married'.

During my first visit to Bob and Sue's house I explained to them that participating in the study involved keeping a photo diary if they would be happy to keep one. *'What should we take pictures of?'*, Bob asked me. *'Of your daily routine'*, I answered. *'What do you not want us to take pictures of?'*, Bob asked. *'I will tell you what you do not want us to take pictures of'*, Bob continued, and he started laughing, *'Me and the missus right? Before you came to visit….' 'We are not even married',* Sue interrupts him. *'We are married, you are married'*, Bob contradicts Sue. *'I was not married'*, Sue continues. *'I am not your toy boy – if we are not married, what are we?!'* Bob tells Sue, slightly raising his voice.

On another occasion Sue told me: *'I had another husband'. 'Here, here, here, how long have we been married?'* Bob asks. *'Not so bloody long',* Sue answers. *'We*

have only been married, er, Sue, Sue, Sue, we have only been married 57 years, that's all'. 'You, well, put it on…. He is making it out what it is', Sue comments. *'How old is our son?*' Bob continues. *'Well, I did not have a son then'*, Sue concludes.

Not only did Sue deny the marriage when asked about it, she also started to deny having a son with Bob. She denied shared experiences that were central to their established roles as husband and wife. Furthermore, she started to embody her denial; a couple of months ago she had decided to start to sleep in the spare bedroom instead of next to her husband. According to her she could not be married to Bob as he was much older than her. She did not realise she was in her eighties too, and when we discussed the pictures in their photo diary she said it was not her in the pictures: *'And the next one, I think it is you and Bob together, is it not?',* I ask Sue. '*No, it is notBob, it is Bob but not me',* she replies. Sue does not think her body matches with who she is, her habitus. She does not remember most recent experiences; this part of her habitus has become inaccessible and as such she only acts upon the part she can access, which does not match the age of her body. Not only does the inaccessibility of her habitus and her body's inability to fully embody the part of her habitus she can access create distress in the outcome of Sue's dialectic relationship for herself, but it also causes tension between her and Bob. Bob's identity is not recognised by Sue: his identity verification has a negative outcome.

There is no mutual recognition of identities in this case, a situation that causes a lot of distress and hurt. Almost every visit, she would make a comment about not being married to Bob. I could tell this repeated denial made Bob upset; he used to make jokes about it to cope. The loss of these shared memories jeopardises Bob's identity as husband. Nevertheless, he strongly believes that the marriage vows they took are important and he will keep caring for his wife: '*Can you tell me about an event that made you feel very happy? I ask Bob. 'I have always been a happy person really. I do not know, I shall say when our son was born. Well, now been married and having a son, you know what I mean?'* Acting upon his ethos, he continues to care although it creates tension in their relationship as they do not share the same common sense anymore.

'Are there any other things you want to tell me about your life to understand it better?' I ask. *'Speaking for me'*, Bob starts laughing, *'She is a ventriloquist'*, he continues. *'We are just taking it as it comes'*, Sue concludes. Making banter about

Sue's painful denial of the marriage by using terms like 'toy boy' and 'ventriloquist' is a coping strategy through which Bob can make sense of the situation and forgive Sue for denying the marriage without having to hide his dissatisfaction about the situation.

It seems like Sue is redefining the relationship while Bob holds on to continuing the relationship as it was. This tension influences not only their relationship but also their whereabouts in other social contexts, which I will discuss further in the next chapter.

6.6.2 Dan and Mary: 'Shall We Go and Visit Mum?'

Mary asks*. 'How can you ask this question? She has passed away forty years ago'*, Dan answers. *'No, she has not, I saw her last week*', replies Mary. *'That is impossible'*, Dan replies. Mary will not believe she passed away years ago. Eventually Dan decides to drive Mary to the graveyard, so she can visit her mum's grave and will understand that her mum passed away. When they arrive at the graveyard Dan says: *'Do you recognise the stone? You chose the wording'*. Mary remembers for a moment and asks Dan to take her home.

When they arrive at their house she says: *'We do not live here'*. Dan replies: *'What do you mean? We have lived here for almost forty years'*. Mary insists: *'This is not our home, I like to go home now'.* Dan tries to explain but Mary will not believe her. He starts the car and drives to the house they used to live at before they moved to their current address.

He rings the doorbell; a woman opens the door. Dan explains to her that he and Mary used to live in the house and that his wife has difficulty remembering they do not live there anymore. The woman invites them into the house, shows Mary the space and explains that she has been living there for many years now. Mary seems to remember, and they thank the woman for her hospitality and drive to their house.

When they arrive home, Mary asks again; *'Can we go home?'* Dan feels tired; how can he explain to Mary this is her home? Eventually Dan requested some information leaflets from the local care charity on caring for someone with dementia. After he read the leaflets he seemed to understand better how to handle the situation. He said*: 'These leaflets I got from the dementia people certainly fit exactly how Mary is'*.

6.6.2.1 The loss of a ‘common sense’

Dan and Mary have lost some of their common sense in this situation. They are not able to remember the same past experiences, they act upon a different habitus because part of Mary’s habitus has become inaccessible. This makes them judge and act differently (Bourdieu 1977; Bourdieu 1990). Mary likes to call her mum because as far as she knows she is still alive. Her mum has always been a central figure in her life as her dad passed away when she was little and she grew up with her mum. Now that she has dementia, visiting her mum is one of the central memories she has. Dan wants her to understand that they cannot visit her mum because she has passed away. Sometimes part of Mary’s habitus becomes inaccessible, but it may become accessible again a little bit later. At first Mary does not believe that her mum has passed away, but she remembers it briefly when Dan reminds her about the fact that she chose the wording on the gravestone. The same happens with their home; she first wants to go to their old house, but when the woman there shows her that she does not live there anymore she seems to remember.

The inaccessibility of Mary’s habitus creates tension between them as Dan tries to gain mutual recognition of their identity as husband and wife who have shared all these past experiences and Mary fails to provide him with this recognition. There is a negative identity verification and it makes Dan insecure.

Furthermore, Mary’s inability to remember in which house they live and to recognize it makes her ask to go home and creates confusion. This shows how her body doesn’t behave as expected when someone is home.

These experiences are exemplary for the experiences of many other couples of whom one has got dementia. In dementia care, practice has been developed to cope with these types of situations. Carers are taught not to argue with someone who has dementia when they are wrong. Instead of confronting Mary with the fact that she is at home or that the family members she would like to visit have passed away, Dan should ask himself why Mary might ask this question and how she might be feeling (Zarit and Zarit 2014) Dan has adopted the advice not to argue and takes her mind off the topic by telling her: ‘It is too late now to call your mum, we will do it tomorrow’. The next day she cannot remember this conversation; the difficulty is that this conversation takes place multiple times a day. Although he knows a bit better

how to handle the situation, it keeps reoccurring, and coping with these situations makes him feel tired.

6.7 The Difficulty of Embodiment when Living with Dementia and Co-morbidities

6.7.1 Jane and Alan: 'I Was Not a Pen Pusher'

Jane asks Alan if he would like to change to the other seat, so he will be better able to hear me speak. She helps him up, so he can walk to the other chair, he moves slowly and sits down immediately when he reaches the chair. Jane takes his special cushion and asks him to get up again, so she can put down the cushion, then she asks him to bend forwards, so she can put a cushion behind his back for support. He makes jokes while Jane is reinstalling him; *'You know how we met? At a dance hall, I tripped over her, she was in the pathway'.*

When he was installed we continued our conversation; '*What type of work did you used to do?'* I ask Alan. *'Well, I try to do jobs for other people but I had to refuse them'. 'You used to do decorating, did you not, for older people?'* Jane adds. *'I used to do, that was when I was not working myself, I felt I could do wallpaper and painting. I think you better do something than just sit there, I used to go anywhere to make a shilling. I was always busy in a way',* Alan explains.

Jane takes over and changes the subject slightly: *'We were always doing things because we have got friends all over, up and down the country. But he cannot drive us there anymore'.* A slight pause follows, and Jane continues: *'We used to do things together every day. Before Alan was ill, we used to go to mass in the mornings, most mornings, and then last year Alan could not, he was too tired or whatever. And since Christmas I cannot go everyday any more either, because I cannot leave him for too long. I still try and go, sort of, five or six days out of seven. Always on Sundays. We still have our daily prayers. And of course, Lent started yesterday, Ash Wednesday, so that is a good season for us to improve our prayer life and deny ourselves a few things. So, we like that, do we not?'*

'Did you share most activities in your daily life?' I ask. *'Well, before Alan first started to be ill, we used to share everything, did we not?'* Jane explains. *'Yeah',* Alan confirms. *'And then when Alan started to be ill, I never realised how much he did, but we get by',* Jane continues. *'Another two to go to get an egg'*, Alan replies. *'Oh, for the fifty golden years. Another two to go'. 'Yeah, that is true, darling, yeah',*

Jane confirms. A slight pause follows, then she continues: *'United we stand, you know, because Alan has good days and bad days and is somebody who is very confused, so it is the sad illness as well as everything else, there is a great sadness with that. But, united we stand, do we not?' 'Yeah',* Alan confirms. He is tired of the conversation and Jane suggests making us all a cup of tea. She gets up and walks to the kitchen.

Alan has lost a lot of weight and much of his mobility due to the several health conditions he has: ulcers, COPD, diabetes and dementia, which have decreased his appetite. He looks frail, as is visible in the picture of the couple in chapter 3. His body is unable to still fully embody his habitus and his past identity as a 'worker', taking pride in being active and helping people. Nowadays he gets tired very quickly; he is unable to walk for longer than twenty minutes and cannot walk very far anymore. He needs help with even the most basic type of movements, like changing seats, and it has become difficult to understand him. He cannot speak loud anymore because his COPD makes it difficult to get enough air, and he finds it more difficult to understand others because of his confusion and loss of hearing.

Although the embodiment of his selfhood has become less because of his health conditions, the physiotherapist who came to their house to do exercises with Alan asked if he used to do manual labour: *'Because she said that when she asked him to push against her hands and everything… and with his knees and lifting his knee up and resisting, she said, did you work outdoors? And he said, yes. He said, I was not a pen pusher. She said, I can tell, you have great strength',* Jane explained once to me. His past work experience was still embodied by this body in some way, although not immediately visible any more.

Alan used to be an active person and he and Jane used to do most activities together; Alan used to drive them everywhere because Jane has never been able to drive. Since Alan's illness they can no longer share all the activities that they used to share. They cannot go to church every day anymore; Jane is even unable to go on her own any more, but they continue to do their daily prayers at home. Their bodies can no longer act upon their habitus as they used to but have adapted to other behaviour that still embodies some of their most important shared values, such as religion, having daily prayers at home instead of attending mass daily.

Also, Jane has developed her own health conditions; back problems, celiac disease and osteoporosis make it impossible for her to take over all the roles and

tasks that Alan used to carry out before. In the next chapter I will discuss how family members help them to cope with the changes in roles in their relationships. Some activities that are good for her she does not do because she feels guilty doing activities on her own that she used to share with Alan: *'I do not swim as much as, well, I have not swum for a long time this year because I hate to go when Alan loves it so much and he cannot go. Our daughter said, well, you should do it for yourself, mum, because I have got osteoporosis in my bones and I need to, um, need to keep them strong. But anyway when the weather improves a bit, we will start, I will start and go back again. But it is just, it is just timings and things now so, changing week by week really. But we seize the day'*. It is hard for Jane to act upon these new experiences (habitus) that ask her to act upon these changes when her body is unable to do so.

This example also illustrates how some of Alan's health needs demand behaviours opposite to those of Jane's health needs. Alan is not allowed to go swimming as he needs to keep the ulcers dry, and Jane should go swimming to keep active with her osteoporosis. Other examples are that Alan needs to gain weight while Jane needs to keep to a strict gluten-free diet and lose weight. Paying attention to these opposite needs takes time during the day. Both Jane and Alan are unable to fully embody their past identities and they need to redefine their relationship taking this into account. This process is stressful as Alan is not able to collect new experiences for his habitus due to his impaired memory function. Instead they hold on to the past, which creates a daily confrontation with what they cannot do any more. They express the wish to keep things the way they are, but the health conditions make it difficult to see each other as the spouses they used to be.

6.8 The Difficulty of Embodiment and the Challenge of the Common Sense

6.8.1 Hamid and Aaisha: It Is a Slow Process but Aaisha Waits Patiently

Aaisha descends the stairs carrying Hamid's shoes and a shoehorn. When she enters the kitchen, she takes a seat at the dining table and puts little knots in the shoelaces before placing them on the ground in front of Hamid. Then she hands Hamid his socks and tells him to put his feet up so she can put his socks on. He seems confused which foot to raise first and Hamid and Aaisha discuss in Urdu which foot he should lift first. It takes him a lot of effort to lift his leg up, Aaisha puts the sock over his toes and tells him to roll the sock up the rest of the foot himself. He

tries but seems to really struggle. Aaisha does not take over but stays patient and encourages Hamid to do it himself, and after a couple of minutes he manages to do it. Then Aaisha tells him to lift his other foot, he lifts his foot, and she puts the other sock over his toes. He seems to struggle even more to roll up this sock; it is a slow process, but Aaisha waits patiently.

When he has got his socks on, Aaisha encourages him to put on his shoes, and he tries to put one on by shoving one foot in the shoe, moving it from the front to the back a little. This does not seem to work, so he decides to stand up, which takes him a lot of effort. He places one hand on Aaisha's shoulder to find his balance while his foot tries to find his way into the shoe. It does not seem to work and Aaisha encourages him to use the shoehorn. He places the shoehorn in the back of the shoe but he is unable to let his foot slide into the shoe.

He sits back down and gives up. Aaisha takes the shoes and walks to the shoe closet in the little hallway to get him another pair. As she takes away the shoes I notice red stickers on them and ask, *'Aaisha, may I ask you why there are red stickers on the back of Hamid's shoes?' 'I did that so Hamid can recognise them when he has to put them back on when leaving the mosque'*, she explains.

While Aaisha looks for another pair of shoes, Hamid puts his slippers back on. *'You might want to keep the slippers off, Aaisha is looking for another pair of shoes you can put on'*, I tell Hamid. Aaisha walks back into the kitchen without shoes and tells Hamid to stand up, take his walking stick and follow her into the little hallway where she has put a pair of loafers ready for Hamid to try on. *'These will be easier for him, they do not have shoelaces'*, Aaisha explains to me. Hamid takes the shoehorn, places it at the back of his left shoe and lets his left foot slide into the shoe. It seems to go easily and smoothly, and he follows the same procedure with the right foot and right shoe. Aaisha takes Hamid's coat and encourages him to put one arm in the right sleeve, then she throws the coat over his other shoulder and tells him to put his other arm in. He does not seem to understand her instructions and shakes the jacket off his shoulder. Aaisha picks it up and lays it over his shoulder again. After the third time they repeat this interaction Hamid puts his arm through the other sleeve and Aaisha can zip up his jacket.

Aaisha steps outside followed by Hamid and me; we leave some room for Aaisha to lock the door. We only walk a short distance, crossing the street to the little park on the other side. The little park looks more like a big grass field with a small

footpath and some benches along its sides. The path first goes downhill to later on climb up again, following the curves of the hills. Hamid slowly climbs the hill, Aaisha first takes his arm to walk beside him, then walks in front of him for a little while and eventually takes his arm again, returning to her place beside him. They do not talk; they just walk side by side with their arms entwined. I break the silence by commenting what a lovely day it is. Aaisha replies by telling me about Hamid's birthday party last week: *'It was really nice, all the family came to visit for a day – the children, the sons and daughters-in-law, the grandchildren, they brought all the food'.* Aaisha looks happy when she talks about the day; she seems to have really enjoyed it. We continue our walk and pass by a man on a bench, who greets them in Urdu. Aaisha and Hamid greet him back while we keep walking.

When we are halfway along the path Aaisha tells Hamid to sit down on a bench, we will have a little rest. Hamid looks tired, a break seems to be welcome. Afterwards we get up again and follow the path uphill, and when we arrive at the top we take a seat on another bench to have a slightly longer rest. Hamid points at one of the trees and Aaisha comments *'That one has been cut down'*, and a small conversation about the trees that grow along the path follows. Hamid gets up, turns around, and starts walking back downhill, and Aaisha and I follow him. He walks a lot faster than before; Aaisha comments: *'This is downhill, that is a lot easier for Hamid'*. When we reach a bench halfway down the path, we sit down and take a break. After the break we continue our walk downhill. A woman pushing a stroller walks our way, and Hamid suddenly stops in the middle of the footpath; he does not know what to do, and the woman with the stroller has to walk around him.

When we leave the park, we stop before crossing the road. A car stops to let us cross, and Aaisha looks at the road and encourages Hamid to cross when it is safe to do so. We only need to walk 250 metres in order to arrive back at their house. When we enter the house, Hamid takes off his shoes and enters the kitchen. He keeps his coat on and tells Aaisha he needs to use the bathroom. Aaisha points to the stairs and says the bathroom is upstairs; she instructs him to climb the stairs and take the second door on the left side. Hamid starts climbing the stairs, using his walking stick to push himself up on each step. Aaisha stands at the bottom of the stairs and continues to make hand gestures indicating where Hamid can find the bathroom. She says: *'You will find it on the left side'*.

When Aaisha is certain Hamid will be able to find the right room, she turns around and walks back into the kitchen, taking a seat next to me on the sofa. We hear Hamid breathing heavily and sighing while climbing the stairs, I ask Aaisha: *'Is Hamid alright to climb the stairs on his own'? 'Yes, he is fine. We also have a bathroom in the garage but Hamid cannot find the way to that bathroom anymore, he can find the one upstairs so he only uses that one'*, Aaisha replies. I ask Aaisha if they ever thought about installing a stair lift and whether Hamid is all right using the toilet on his own. Aaisha tells me someone from the council is coming to talk to them in two weeks to see their house and tell them how they could offer support.

6.8.1.1 24/7 Care

As illustrated in this vignette, Aaisha has to provide 24/7 care for Hamid, she needs to help him with almost every task. In most couples of whom one cares for the spouse with dementia this is the case (Jansson et al. 2001; Walters et al. 2010). Although going out for a walk is an activity they both enjoy doing, the activity is mostly centred around fulfilling Hamid's needs; Aaisha mostly follows him and looks out for him. When he gets up after a little break, Aaisha and I follow him back to the house without questioning. Like in most spouse care relationships in similar contexts (Walters et al. 2010), there is little reciprocity in this scene apart from an acknowledgement by Hamid that Aaisha is joining him in this activity by initiating a small conversation about the trees and allowing Aaisha to walk arm in arm with him for a while. In general, Aaisha waits patiently and gives Hamid the space to do as much as he can still do independently, but she clearly needs to instruct and encourage him.

Furthermore, this vignette shows how Aaisha becomes a mediator between Hamid and others in the social space, like most carers in similar situations (Jansson et al. 2001; Walters et al. 2010); she needs to interact with drivers to make sure they stop, she decides that it is safe for Hamid to cross the street and she talks to the local council about possible adjustments to their house. It becomes clear that Hamid would not be able to go for this walk without the assistance of Aaisha. In fact, he is unable to do most of the daily routine activities independently as he cannot seem to find his way around the house. He has lost access to the memories of where the

downstairs bathroom is and needs instructions to find the upstairs one. His body responses to this inaccessibility of his habitus by being lost in the house.

This is only one part of an average day for Aaisha and Hamid but it shows how Aaisha's activities and role are built around Hamid's needs. We could identity these observations as challenges for Aaisha, but when we analyse these challenges using an identity perspective it becomes clear that they are less obvious and indirectly are related to other challenges.

6.8.1.2 'He is my duty'

As illustrated in the vignette, having the whole family together at their house to celebrate Hamid's birthday made her happy; their photo diary contained multiple pictures of this event in which both Hamid and Aaisha are smiling. This event confirmed Aaisha's role as 'home maker'; she provided a family home where the whole family came together to celebrate Hamid's birthday. This is illustrated well by a conversation I had with Aaisha about her life history: *'What did you do when you left school?'* I asked. '*Work in the house. I had to attend training at home, I was...cooking, sewing and like that. My mum said: "You, learn this, okay? Learn this sweeping, this work, house jobs"'. 'Would you say that your house is still important to you?'* I asked. *'Everything is important in the house, because I do everything, cooking things, sewing things and machine',* Aaisha replied. Similarly, caring for Hamid is an act that confirms her identity and which she likes to perform.

When I ask Aaisha about her motivation to care, she tells me it is her duty to care for her husband. In their relationship he has always been the main decision maker and she has accepted his decisions and adjusted her life to them, which can most clearly be illustrated by their immigration to the UK: *'One day he came home and said: The English government is in need of teachers, they will provide the visa. We had only been married for six months, I was expecting our first child, he had a job as a teacher in our hometown and we had just moved house. Still he decided to go to England and I had to move back in with my mother for a year. In those days I felt lonely; my husband was in another country and I could only join him a couple of months after I gave birth. I liked to join him as soon as possible and had to travel to England on my own with my six-month-old son, while in Pakistan I was not allowed*

to leave the house on my own. When in England I gained the freedom to leave the house on my own, that freedom is all right'.

Just like most spouses caring for a partner with dementia (Samsi and Manthorpe 2013; Sinclair et al. 2018) Aaisha took on the role of decision maker/manager of their lives; before, Hamid used to make the important decisions for the family on his own, like his decision to move the family to the United Kingdom. It was not an easy time for Aaisha: she had just started her life as a married woman and was expecting a child and keeping a home when Hamid decided to move away. She could not stay in their house, which must have meant a drawback for Aaisha; she had just obtained the status of a married woman who runs her own house and had to move back in with her mum, obeying her mum's house rules again. She followed her husband to England as she wanted to be with him again and viewed him as 'her duty'; it is her duty to take care of her husband and follow his lead.

Although Aaisha is used to adjusting life to her husband's needs, she is not used to being the decision maker; this has implied a change in their power relationship, which has caused disruption. As shown in the last chapter she feels like she 'lost her husband'. She needs to adopt the role of decision maker which does not fit with her well-established identity as 'home maker'. Furthermore, these changes also challenge Hamid's identity as head of the family and decision maker.

Aaisha's well-established identity according to her habitus and the common sense of their cultural group is challenged as she needs to adapt to a new role and its connected behaviour of being the decision maker and mediator of her husband's interaction in social space. Hamid also cannot embody his role as decision maker any more either, although that is the role as expected by his habitus and common sense. This means that the couple needs to change its common sense and accept the new equilibrium, which is challenging when others in their environment do not accept this change and keep acting upon their past habitus and common sense.

These changes cause stress and disruption, especially since others do not seem to recognise her role as decision maker yet. On this I will elaborate further in the next chapter.

6.9 Accepting the Redefinition of the Relationship

6.9.1 John and Diane: 'You Know, He Says it is Getting to a Point Where I Have Got to Look After Myself'.

'Because the social worker says that J's getting too much to handle. He does not know my blood pressure is up. I have not told him; I am not bothering him with that. But, because I think it is to do with my… situation and weight, so it is the two things together'. As described in the first quote of the chapter, Diane struggles with accepting being the carer and admitting that she does not view her husband as a husband any more. Still, she finds it hard to give up on caring for her husband even though her own health is under pressure. It is often hard for carers to pay enough attention to their own health conditions, and get support from their spouses to do so, while caring (O'Shaughnessy et al. 2010). In this example, Diane cannot lose weight and pay attention to decreasing her blood pressure; in fact, the stress of the caring might contribute to her conditions.

She explains a bit how she struggles with the being kind to herself but also knows she should*: 'I am very good at being kind to other people who are struggling and I have had it said to me that you are actually not very kind to yourself sometimes, because you do not do the things you might say to somebody else who is unhappy, you are not applying it to yourself. I mean, most, a lot of what I do now, is driven by John's needs. So, I would quite like to do some things that I want to do. Accepting the carer identity is so hard. It takes a lot of coming to as well, but with people around me I can do it'.* Not being able to think about your own needs is an often heard experience among carers (Parker 1992). Although many carers acknowledge that they do not have much room to think about their own needs, they also struggle to admit they are carers (Newbronner et al. 2013).

Over time she came to accept her role as a carer for her husband and, as explained in the first quote, the way she loved her husband changed and she found it easier to deal with being a carer than a wife. She does not identify as the wife anymore; this happens often to caring spouses due to the changing circumstances (Chung et al. 2008). Diane describes noticing similar changes in her husband's attitude to daily life: '*It is as if he was living in a complex. You know, I mean he does not seem to know where everything is, and sometimes he will say to me something like – I will be sitting maybe watching a bit of television and he might say to me, should you not be working? And it is as if he thinks I am the care assistant or*

something… or whatever. Which is quite interesting. But you know, he treats the situation in a different way. He puts his – you leave your stuff in the bathroom… he will take it into his bedroom, his toilet bag'.

Diane struggles to make sense of her new identity of being a carer for her husband and questions her role as wife and carer. Eventually she accepts the identity of being a carer and embodies this new role. Her body is under increasing pressure as she takes up these roles and eventually it is not able any more to adapt to these changes. She is advised to abandon some of the tasks of this role and ask others to help her. This causes distress for Diane. Although being the carer creates continuity for Diane, her body cannot fulfil this role.

John's changes in behaviour and his need for personal care made it more difficult for Diane to still view their daily life together as being married. She started to perceive it as a caring situation. Twigg (2000) comments that it is difficult for the person who is cared for to keep their grown-up identity as they have to accept all sorts of personal care and need to use products such as pads.

When Diane accepted her new role, she started to view John's behaviour differently and started to make sense of it through her new habitus; taking his toiletry bag to the bathroom and asking her if she did not have to work made her feel like he was recognising her as being a carer and as if he was interpreting their house as being a care facility. This has also helped her to justify her new role and find 'mutual recognition'. But her embodiment of being a carer was also influenced by others who according to her 'helped' her to accept these changes as described in the opening vignette of the chapter. This process was hard because John's behaviour challenged her identity as a wife. She decided to adapt to his behaviour and accept the carer identity to find confirmation of this identity.

6.10 The Dialectic Relationship, Identity Theory and Understanding the Relationship of the Couple

Bourdieu's dialectic relationship raises awareness of the importance of the relationship between the habitus, common sense, environment and body to understanding the disruptions that couples experience in their relationship. How people interact is influenced by the dialectic relationship between their past experiences, their ethos, their shared experiences and the ethos with others with

whom they share a group identity: in this case their spouses, the environment in which they are situated and the ability of their body to behave as expected. When someone develops dementia and co-morbidities this dialectic does not always still function well.

The function of the habitus is challenged because the dementia creates a loss of memory and an inability to create new memories. Besides, the dementia and co-morbidities can limit the ability of the body to embody the habitus. The cognitive impairment of dementia and the co-morbidities limit the function of the body to fully embody the selfhood of the person, as is shown in the example of Jane and Alan and of Sue, whose body is too old to still embody the habitus that is accessible to her. Furthermore, these aspects can also challenge the function of environment in the dialectic relationship, as people with dementia do not always recognise it anymore, so the familiar can cause distress, as with Mary who does not recognise her own house and Hamid who cannot find his way to the bathroom.

These outcomes provide an opportunity to critically reflect on the concept of embodied selfhood based on Bourdieu's dialect relationship as developed by Kontos (2004;2005;2006). She argued that nevertheless the cognitive impairment people with dementia were still able to embody their selfhood and to behave accordingly to circumstances. The examples in this chapter show how the cognitive impairment and other health conditions do influence the ability of people with dementia and co-morbidities to fully embody their selfhood and to be able to behave as expected. Furthermore, I showed how this does not only influence someone's ability to embody selfhood but also impact on their relationship with their spouse, this is especially the case when the common sense is challenged.

The common sense can be challenged when one partner does not remember important experiences that were part of the shared common sense. This can create tension, as with Sue who does not remember being married or having a son with Bob. Besides the tension, it also makes the other people who used to share this common sense second guess this common sense, making them feel insecure, and may cause emotional distress.

When the common sense is challenged, the individual habitus from the members of the group is also challenged, in this case the habitus of the spouses. This is illustrated in Bob's banter and the fact that he keeps asking for confirmation that they are married, Dan's deciding that he needs to ask for information about

Mary's dementia, Diane's embodying the carer role and identifying more easily with being a carer than a wife and Aaisha's having to become the decision maker in their relationship.

Sometimes the dialectic relationship does not function well, while at other moments it does function as expected again. As shown in the example of Dan and Mary, inaccessibility can be temporary; at first, she does not believe that her mum has passed away but when Dan shows her the gravestone for which she chose the wording she remembers. In that moment the environment, the gravestone, connects with her habitus and it becomes accessible for a moment. Her body responds to this recognition, and she tells Dan she remembers and would like to go home. When they arrive at home she does not recognise the environment; her habitus has become inaccessible again and the environment does not necessarily prompt her to behave as expected.

When the dialectic relationship does not function well it also makes the couples question their roles and identities in the relationship because they used to get confirmation for their identity. This confirmation could come either in the spouse's ability to remember an important shared memory like being married or recognising an environment that symbolises an important shared memory, like the house they have lived for many years, or in their body's ability to embody part of their identity that confirms the other spouse's ability, like performing a role that they always have in the relationship. For example, in Hamid and Aaisha's relationship, if Hamid had still been able to be the decision maker it would have confirmed Aaisha's role in the relationship and her identity as his wife.

An identity perspective based on identity theory and Bourdieu's dialectic relationship provides a better insight into the relationship between different aspects of the daily life of these spouses that we know are important and influence each other – relationship, co-morbidities, identities, roles, the daily life experience – but for which we have not yet developed an interaction theory. This perspective provides a theoretical approach in which these relationships between different aspects of daily life become clear on an analysis level. This helps us to look at the disruptions in the relationship of the couple as being embedded in the daily life routine and part of the interaction between the body, habitus, common sense and environment.

When we use this perspective to look at specific spouse care challenges, it can illuminate what different aspects of the dialectic relationship are creating this

disruption and how the disruption may create other disruptions, as is well illustrated in the example of Bob and Sue. Sue's inability to access certain parts of her habitus and her body responding to what she can access create tension in her relationship with Bob and make Bob insecure about his own identity and position. This perspective also gives us an opportunity to critically reflect on the role of environment as an aspect that can cause disruption. As discussed in Chapter 4, the familiar environment can create confusion and disruption for someone with dementia, even though in policy the function of a familiar environment in preventing unnecessary confusion is emphasised (NHS 2015). In the relationship of the couples, the inability of the spouse with dementia to recognise the familiar environment can be especially disruptive because it is usually connected to the common sense that creates a fundament for their relationship.

Identity theory has also contributed to the perspective offered as it helps us to view the dialectic relationship described by Bourdieu as an ongoing process that is constantly changeable over time, in different situations and in relationship to different people with different habitus. The example of Dan and Mary clearly illustrates this changeable nature; in one moment their common sense is challenged and a moment later it is confirmed again.

6.11 Summary

As suggested in the literature synthesis in Chapter 2, all couples go through a process of redefining their relationship when confronted with dementia and co-morbidities. All these processes are influenced by identity recognition and development. Using identity theory and Bourdieu's concepts of habitus, common sense, environment and the body and their dialectic relationship, I showed how complex the redefinition process of their relationship is from an identity perspective for couples living with dementia and co-morbidities. The recognition of identity in the verification process makes the 'redefinition process of the relationship' troublesome and difficult when elements of the dialectic relationship do not function as they are supposed to, for example, when the habitus is inaccessible or the body is unable to fully embody the habitus. Challenges in the couples' relationship redefinition process are influenced by or originate in an interplay of the habitus, common sense, environment and body.

The plurality and situation-based character of identity and the ongoing processes of identity verification demonstrate that the process of redefining the relationship that couples living with dementia and co-morbidities experience is not necessarily a linear process of sustaining couplehood, maintaining involvement and moving on, after which a couple decides to continue as ‘we’ or become ‘I’. They might still identify as being husband and wife at one moment while in another context they refer to being a carer or to individual identities. The spouses have always had both their individual identities and their shared identity based on being married. They have always embodied these multiple identities in different contexts; these can still co-exist when dementia occurs.

In the next chapter I will explain how others play a role in how these couples cope with the challenges associated with caring for each other and their health conditions, and how they are identified by others in the community and their social networks, which can influence their and their access to health care, support service and informal support, as well as their roles, positions and involvement in the community.

Chapter 7

‘Who Could That Be?’:

Dementia, Social **Networks and the Community**

Ding-dong, ding-dong, the doorbell rang, and Aaisha got up to open the front door. Aaisha said: *‘Who could that be?’* They were not expecting any other visitors this afternoon. As Aaisha was walking to the door, I looked out of the window and noticed two police officers standing outside. Aaisha opened the door and talked to them. I heard them speak in Urdu, I picked up a couple of words Aaisha said – ‘memory problem’ and ‘interview’ – and overheard the police officer explain that he wanted to enter the house to check up on Hamid. One of the police officers entered the kitchen, shook my hand and said hello. Hamid stood up, smiled and said: *‘That is the police’*. The officer turned to Hamid, shook his hand and asked him if he was doing ok. Hamid said, *‘Yes’*. When the police officers saw that everything was fine, they said goodbye and left the house.

Earlier that afternoon, Aaisha had told Hamid she was going to take a bath upstairs. Hamid quickly forgot what Aaisha had told him and wondered where she was. He looked for Aaisha but could not find her, so he picked up the phone and dialled 999. When Aaisha came downstairs, she noticed that Hamid had called someone and listened to the recording on the phone: *‘She has left me, my wife has left me, now I am all alone’.* It did not surprise her; he had at other times gone outside and told neighbours that she had left him.

Aaisha commented that she was happy that the officers spoke ‘her language’. Aaisha and Hamid had moved from Pakistan to England fifty years ago, and although Aaisha had developed a workable knowledge of English over the years she considered Urdu to be her language. Before Hamid developed dementia, he used to speak English fluently and was the communicator between the family and non-Urdu speakers in society. Aaisha had always been a housewife and did not interact much with English speakers. Since Hamid had developed dementia she had to take over his role of interacting with English speakers on their behalf. Part of this role was interacting with interacting with authorities, including police officers, health care professionals and service providers. Because of her limited knowledge of English,

she would not always be taken seriously, as illustrated by the following scene from my fieldwork:

Aaisha entered the room with a paper with phone numbers in her hand. I asked her if she had managed to get hold of the GP practice. She told me they hung up on her but she would ring again. This time they did not hang up on her. The volume of the phone was quite high, so I could hear the women at the surgery speak to Aaisha. Aaisha explained that she was calling on behalf of her husband, and the women on the other side of the line asked her if he was around himself. Aaisha explained that he was around but not able to talk to her due to memory problems. The woman in the surgery kept insisting on speaking to her husband; Aaisha persisted in saying that he would not be able to speak to her. After the woman asked her for the third time she replied: '*I am his wife, you can give me the information'*. But the woman at the surgery insisted on speaking to Hamid. Aaisha passed the phone to Hamid. In the meanwhile, Hamid had been reading the consent form for the study and was just about to ask me a question, and when he received the phone he was confused. The woman on the other end of the line asked him if he was Hamid. He did not answer her question and replied something in Urdu instead. The medical receptionist kept asking questions which he could not answer. Aaisha looked at me and said, *'I told them so'*. She asked Hamid to pass her the phone and continued her conversation with the receptionist.

In general, she had difficulty accessing and communicating with services, and once she had identified services that spoke Urdu they did not always reply to her request for support. Another time I asked Aaisha if she had managed to contact a social worker about the respite care she would like to access. She told me that she called a local charity that offers support in Urdu but they told her their manager was in a meeting and would call her back. They never called her back; she tried to ring them back herself several times but the manager was always out. She made a hand gesture indicating that she was fed up with it and would not call them again. Having difficulty communicating with and getting access to services is frustrating for Aaisha as she performs 24/7 care for Hamid.

7.1 Introduction

As shown in the vignette above, identities and roles are established not only between the couple but also through interaction with others in social situations, police officers, neighbours and employees at GP practices. In this chapter I would like to show how the social interaction in which identities are established takes place not only between the couple but also within their broader social network and interaction with the community and some of the services that are based there. An identity perspective could help us not only to understand better the challenges that the couples have to cope with in their relationship and daily routine together, but also to understand their interaction with their social networks and community, and their roles and positions in these social realties.

First, I will give a brief background on how the topics of social networks and community have been studied within the dementia care discourse so far and argue how an identity perspective could help us to develop these topics of research further. Afterwards, I will discuss different vignettes from my project that illustrate how an identity perspective could help us to understand better the role of social networks and the community in the daily life of people with dementia. Finally, I will summarise the argument.

7.2 Background: Dementia, Social Networks and the Community

As noted in the previous chapters, carers often become mediators between the person with dementia and their surroundings and social network (Jansson et al. 2001; Walters et al. 2010). Sometimes carers have to start managing the social relationships on their own and experience a decline in social networks (Vikström et al. 2008). As shown in the systematic review of Perry-Young (2018), social networks and social relationships are a well-established research topic within dementia care research. They have been researched mainly in connection to help-seeking behaviour and as a possible preventive factor for the development of dementia (Fratiglioni et al. 2000; Crooks et al. 2008; Kuiper et al. 2015). These social relationships and the available care and support are situated in various social spaces including the community.

The Alzheimer's Society in the UK introduced a programme that aims at a 'dementia-friendly' community. 'Our dementia-friendly communities programme encourages everyone to share responsibility for ensuring that people with dementia

feel understood, valued and able to contribute to their community' (Alzheimer'sSociety 2018).The concept has also been picked up in the dementia care research (Bartlett 2016; Wiersma and Denton 2016b; Ward et al. 2017).

What we see in these examples is that while neighbouring is important for emergency situations, it also forms part of the daily, often mundane activities of everyday life in ways that enable people to continue to maintain a degree of independence. However, people living with dementia are not solely recipients of neighbourly support, but rather engage in recursive acts – looking out for other neighbours in ways that have been largely overlooked in research, which has rather narrowly focussed upon carer–cared for relationships (Ward et al. 2017: 7).

The quote from Ward et al. (2017) is one of the findings from a recent study that analysed the lived experience of people with dementia in the community. It shows how the dementia discourse has moved on to focussing on the capabilities of the person with dementia in society and how this can help us to challenge the stigma and note the importance of more holistic research into the lived experience of dementia. But it is also a problematic statement as it shows how there is a bias within the dementia care discourse that people with dementia would not be actively involved in their communities, as if a dementia diagnosis changes a person's identity, and we need these study results to challenge that assumption.

Twigg (2006) explains in her work *The body in health and social care* that this problematic statement originates in assumptions we have in society about the ability of elderly people who lose certain abilities. According to her when people age and develop health issues and disabilities they will find it difficult to perform taken-for-granted routines that are part of being involved in the community and daily life. These routines are often performed by the individual, it is expected of adults especially that they can take care of their own bodies. As a result of the failure to perform these routines on their own, their identity of being an adult is questioned. Gilleard and Higgs (2000) argue that as a consequence elderly's roles in society are underestimated.

Although this statement is true in certain contexts, it does not apply in every context of elderly people living with or without health conditions and disabilities, such as people with dementia and co-morbidities. As shown in the previous chapters,

illness and daily life are intertwined, people actively negotiate their dementia diagnosis and choose in which contexts to accept and disclose it, and people hold multiple identities anyway. When someone is diagnosed with dementia, the accompanying identity does not necessarily mean that the person loses his or her identity as neighbour and part of the community.

Ward et al. (2017) also show how connections like going to the same hairdresser create belonging for people in the community. This belonging influences their roles, identities and positions in the community. As shown before, identity is a process and imbedded in daily life; people will not stop carrying out these daily routines once they have received a diagnosis. The assumptions that people would lose their belonging in the community and that others in the community need to help them to keep the ties are problematic.

In the dementia-friendly communities discourse we should step away from the idea that someone either loses or keeps their involvement in the community and view it instead from the perspective of identities and roles within the community that are part of a process that changes over time. Bartlett (2016) points out that the concept of dementia-friendly communities is still undertheorised. An identity perspective will enable us to look at dementia-friendly communities as places where people act upon their plural identities, which should be accepted and acknowledged. Such a view could contribute to creating an insight in the social position of people with dementia in their communities and ultimately the society.

Another contribution of this study to the concept of dementia-friendly communities is its long-term perspective. Wiersma & Denton (2016) already discuss how looking at how individuals received help from their social networks in the past could help us to predict the type of support they will receive when they develop dementia. They suggest that a better idea of how people's social networks provide help and support over their lifetime can help us to understand how these networks could provide help when someone develops dementia. This shows the importance of an understanding of people's identities, roles and positions within their social networks and communities over a longer amount of time to provide them with tailored care and support.

I will now present five examples of how an identity perspective can provide this understanding drawing up on examples from my fieldwork.

7.3 'We Know the People in the Neighbourhood'

'Our oldest son asked us to live with them, he build us a room and bathroom at his house, he told us to sell our furniture and move in with them. I would like to move to a smaller house for me and Hamid keeping our own things but I do not want to move in with my son and daughter-in-law. Our children do not want us to move to a smaller house, so I told them we are staying in the house we are living now. I like the location of our house – it is close to the mosque, the shops and the centre of town and we know the people in the neighbourhood' (Aaisha).

Although Aaisha cares for Hamid every day and acts as the mediator between him, other people, institutions, medical experts and the environment, as shown in the opening vignette of this chapter, their children do not always seem to respect her wishes and leading role. Instead of supporting Aaisha and Hamid to move into a smaller house where they might be able to manage better on their own, their son offered them a place in his house, denying Aaisha the possibility of remaining the home maker and primary carer. The eldest son probably wanted to take responsibility for taking care of his parents, just as his parents had taken care of Hamid's mother in the past. Being the eldest son, he tries to do as he should according to cultural expectations, but this role challenges the agency and decision-making power of his parents. Also, he denied them the possibility of bringing their own furniture and objects; he told them he had bought nice new things and they should give away their stuff to poor people. He probably meant well, providing the best he can for his parents, but in fact he would be taking away all their possessions, making them more dependent and taking away the part of their identity that is attached to these objects.

Aaisha has difficulty establishing her new role and identity as the 'head of the family', main decision maker and mediator of the family as shown in the previous chapter. This status and role is not always acknowledged by health care and service providers and family members. The police officers in the opening vignette who insist on talking to Hamid on the one hand acknowledge Hamid's agency but simultaneously undermine Aaisha's status, identity and role. She feels unheard; she shares her knowledge about the situation, but still the service providers insist on talking to him.

7.3.1 Family Support

Hamid and Aaisha's children all live in other cities quite far away, making them unable to provide daily support and care. One of their sons is a GP and one of their daughters a pharmacist: they also have a professional background which might create a bigger incentive to care. To a certain degree they let their children take up a care role; they discuss with their son who is a GP the type of medications they are taking and they accept weekly support from one of their daughters to take them to the supermarket and enjoy the food she prepares for them.

The children are important in Hamid and Aaisha's life. Although Hamid has had dementia for several years, confuses many things and is unable to remember many events, he does remember some family events, like his last birthday party. He often finds it difficult to explain things in English, needs a lot of time to find words and sometimes coughs as if he is going to cough up a word; he slowly says: *'All my children……. all my children…… everyone was there'.* He takes a breath and says: *'I wish you could have been there'.* I reply: *'Yes it would have been a lot easier if I could have seen it so you did not have to explain it to me'.* This event was also important to Aaisha; their photo diary contained only nine pictures and five of them were taken at the birthday party

The help they accept from their daughter is important to them; without it they would not be able to buy their weekly groceries. Hamid lost the ability to drive and Aaisha cannot drive, so they are unable to visit certain shops on their own. There is a little supermarket down the road but Aaisha does not like to go out to the shops and leave Hamid on his own at home. She sometimes does so when he is asleep and they really need some products. In the past Hamid and Aaisha used to visit their children themselves by car, but nowadays they are dependent on the visits their children pay them. Losing the car makes Hamid and Aaisha housebound and unable to visit friends, family and shops outside of walking distance. Sometimes they take the bus or pay for a taxi when they have a medical appointment.

Their son's offer for them to move in with his family would place Hamid and Aaisha in a situation where they could receive day-to-day support in care from family, and the children would be able to drive them places. But a house move like this would also mean a disruption of their daily life routines, which are situated in their current neighbourhood. Hamid would not be able to go to the same mosque any more, where everyone knows him and his cousin walks him home, and he would not

be able to go to the local community centre any more, where the members still acknowledge and respect his former role as head of the centre. They still invite Hamid to attend the meetings of the board of the centre, even though he is not able to go any more. The people in the community still acknowledge his past social identity and sustain part of his selfhood. Aaisha would not be able to attend her women's group anymore and would lose the friendships she has built up there. Also, they would have to access other health care and support services, including changing GPs while they are happy with their current GP. Moving in with their children would create a major disruption in their daily lives and identities.

7.4 'It Was the Police, They Found Sue'

The week before, Bob had told me that someone from the city council would come to visit next week: *'Our son told me that I need to ask about services that can offer help, so I contacted the city council, someone will visit next week'*. When I arrive at Bob and Sue's house for my weekly visit I notice a black car parked in front of the house. When I enter the house, Bob says, '*You are late'*. The bus I took had been delayed and I arrived ten minutes late. I introduce myself to the social worker and ask him if he minds if I use this meeting as a source of data. *'Bob already told me about your project, that is fine'*, he replies. *'Actually, I just finished here, I only had to check Sue's financial situation to find out if she has to pay for her GPS tracker herself'.* The council had offered them a GPS tracker so Bob would be able to find out where his wife is when she goes out wandering. *'Where is Sue, actually?'* I ask*. 'She was already out when I arrived and Bob told me she did not take the GPS tracker with her'*, the man from the council replies.

Ring, ring, ring – Bob gets up to answer the phone. I continue the conversation: *'What other services can you offer Bob and Sue?' 'At the moment we cannot offer anything else since Bob tells me Sue does not need personal care services'. 'Okay, but could you offer them some respite care?'* I ask. '*Well, we offer respite care; Sue could visit a day centre or she could stay at a home for a couple of days, but Bob told me she would not do that'.* He takes a slight pause and continues, '*Bob told me she denies having dementia and goes out wandering a lot, not just around the corner but she takes the bus to another town'. 'Yes she does'*, I confirm*. 'I usually meet carers who are struggling to cope with the care and become ill*

themselves, but Bob seems to cope well', he comments*. 'Well, every care situation is different',* I reply.

I did not actually know whether Bob's coping strategies were necessarily good. He just did not directly show how difficult it was but tended to joke about it instead. I decided not to comment. It was Bob's decision on what he wanted to share with the council worker.

'*It was the police, they found Sue'*, Bob announces as he walks back into the living room*. 'I should go and pick her up at the bus station in another town'*, he continues*. 'I am glad they found her, and I should get going so you can go and pick up your wife'*, the man from the council replies. Bob cracks some other jokes about caring and says goodbye to him. *'I had a bad day this morning, but your jokes made my day'*, the man of the council concludes, and he gives Bob some other information flyers and tells him to call if he needs more information. Bob thanks him for the visit and shows him out. '*Do you fancy a ride out?'* Bob asks me. '*We should go and pick up Sue'*.

Earlier that day Sue had decided to take the bus to her 'home town'. *'I can imagine how she must have got lost today, last week when I joined her on the bus to her 'home town' she seemed to get confused along the way as well'*, I tell Bob*. 'I do not know, I told her about the visit of the city council and she still decided to go. What does she actually do when she goes on these bus rides on her own?'*, he asks. '*I could tell you about the bus ride I accompanied her on last week'*, I suggest.

7.4.1 The Bus Ride

When we arrive at the bus stop, Sue says*, 'We might be waiting quite a long time, maybe even more than thirty minutes'*. She takes a place on the bench and taps with her hand on the empty place next to her, indicating I should take a seat next to her. I had checked the time table when we arrived, so I tell Sue, '*The bus will arrive in ten minutes'*. Sue takes her bag and starts searching for her bus pass. After she finds it she stands up and says, *'Stand up, the bus might drive past us'*. We stand up and try to see if there is a bus approaching, which is not easy as some bushes are blocking our view. When a bus approaches the roundabout a bit further up the road, Sue says: *'Maybe it is that green bus'*. I can tell by the number on the bus that it is not the right one. Later that day I realise that Sue could not read the number because she had been wearing her old reading glasses instead of her new distance glasses. *'Are*

you not cold? Do you have a coat with you?' Sue asks. Before we walked to the bus stop she asked me if I needed a bag to put my jeans jacket in as it was a warm day, and I told her I would put the jacket in my backpack.

After ten minutes no bus has arrived yet. We wait a bit longer and at a certain moment another bus stops at our bus stop. I ask Sue, '*Can we take this one too?' 'No, it will not go to my home town',* she replies. We have to wait longer and I become a bit impatient; both of us make some complaints about the bus being late. *'Sue would you maybe like to sit down on the bench while we wait? I could tell you when the bus arrives'*. Another bus with a different destination arrives so we keep waiting. A bit later a man joins us at the bus stop, and Sue asks him: '*Are you going to Sheffield too?' 'Yes I am, the bus will arrive soon'*, he replies. Five minutes later a bus arrives. '*Do you drive to Sheffield?'* I ask the bus driver. *'No, I do not, that bus only goes once an hour'.* The timetable at the stop said it went twice an hour. In the meanwhile, Sue gets on the bus. *'It is not the right one – it does not go to Sheffield'*, I tell Sue. *'Do you go to Sheffield?'* she asks the driver. '*No, I do not go there, love'*, the bus driver replies. Sue gets off the bus again and I look up on my phone when the bus is supposed to arrive. *'The bus is 20 minutes delayed, we need to wait longer'*, I tell her.

When the bus finally arrives, Sue takes her bus pass out of her bag and steps on the bus. She picks a seat in the front, the bus shakes a bit as it leaves the stop and she comments *'It is a bit bumpy'* and starts to smile. This happens a couple of times during the bus ride. At the next stop a woman boards the bus. '*She is big'*, Sue comments, nodding her head. Later on, a group of pupils enter the bus; two of them are breaking some poster frames. Sue becomes annoyed and tells me: *'I am going to tell those girls to stop'. 'I know it is not right what they do, but please do not get up while the bus is driving, you might fall'*, I reply. *'It are them, those lashes'*, Sue says and points her finger. The girl in front of us turns her head and says: *'They are always making trouble on the bus'*. While Sue tries to get up the girl offers to hold her coat. *'Please sit down, I will tell them off when we leave the bus'*, I tell Sue. *'These girls are not disciplined enough'*, Sue replies.

During the bus ride I ask Sue multiple times what towns we are passing through, but she never seems to know. The bus ride takes a very long time; we spend about an hour and thirty-five minutes on the bus. When we arrive in Sheffield Sue seems confused and is not sure she would like to alight the bus. When we do,

she asks: *'Where do we have to go now?'. 'Let us just go where you usually go',* I reply. Sue takes this bus every day, sometimes even multiple times a day, but it seems like she does not know where to go once she arrives. *'Shall we have a cup of tea?*' I suggest. *'Yes, I would like a cup of tea'*, Sue replies. We choose a coffee place and have some tea and cake.

After we have our cup of tea I check on my phone when our bus goes back. I read that the last direct bus goes back in thirty minutes. *'Shall we walk to the bus stop – our last bus goes in thirty minutes?'* I tell Sue. *'Why, I do not want to leave yet'*, she replies. *'We need to catch this bus, it is the last direct bus'*, I explain. I am a bit worried whether we will be able to catch it; Sue walks slowly. When we step outside, Sue is confused. *'How do we go to the bus station?'* she asks. I point out where the bus station is and slowly we make our way to the stop.

'It seems like sometimes she knows where to go and sometimes she doesn't', Bob concludes. We have just arrived in the town where Sue will be waiting for us at the bus station. Bob does not know this town well and he opens his window to ask someone directions to a parking space. When we have parked the car we make our way to the bus station; it is quite a walk and we need to cross the local park. *'Why could she not just take the bus to a town closer to our house?'* Bob comments.

About forty-five minutes after the phone call from the police we arrive at the bus station. Sue is sitting on a bench with a bus driver next to her. '*Are you the husband?*' the driver asks. *'Yes, I am'*, Bob confirms. *'Well your wife became a bit confused when on the bus, first she stepped on the bus to one town, then she told me she actually had to go to another one and then she changed her mind again wanting to catch the bus to her original destination. She seemed confused and I asked her to show me her bus pass. Instead she opened her bag and showed me quite a lot of cash*. *I decided to call my boss and was advised to stay with your wife during my lunch break at the end destination of my bus ride. Meanwhile, they would inform the police, who would call you'*. Bob and I thank him for staying with Sue, making sure Bob was informed and staying with her during his lunch break. *'No problem, I am happy to help. The bus company made us take a dementia awareness training, I just knew it was not right and should help',* he explains. Sue opens her bag and offers the driver some money to thank him for helping her out. He declines, gives her a hug and says, *'I hope you stay well'*.

One moment Sue knew where to go, how to recognise the right bus, where to find her bus pass and how to interact with others on the bus. Other moments she was confused and did not know where to go and what to do. This example also clearly shows how dementia and co-morbidities complicate each other. Due to Sue's dementia she did not realise she was wearing her readers instead of distance glasses; this created a problem with eyesight and could have enhanced her confusion due to the dementia.

Even though she sometimes got confused when taking the bus on her own, she was determined to keep going places on her own by bus. Sometimes she found her own way back home, but other times a police car or taxi would arrive at their house with Sue in it. The first time this happened, Bob was advised to put an address card in Sue's handbag with his contact details, but Sue used to lose this card so later on a council worker suggested using a tracker. A small, square black box on a key cord with a GPS tracker in it would help Bob to know where Sue was. If she did not arrive home at the time he expected her, he could call the tracker company and ask them where she was, so he could go and pick her up.

Sometimes the tracker would work as expected and Bob would be able to find out where Sue was, get in the car and pick her up. Other times it did not help them; sometimes the battery went flat, Sue had left the house before Bob had had the chance to put the tracker in her bag, the company had told him a location but in the meanwhile Sue had travelled elsewhere or Sue lost the tracker. Luckily the bus drivers started to get to know Sue and sometimes stepped in when they noticed she was confused. They all treated Sue like any other passenger that could travel independently on the bus, till the moment she got confused and they treated her as a 'person with dementia' for whom they had to care. Bob is treated as the carer but the type of help they offer him depends on Sue's wishes and whereabouts; when she refuses services and help, they cannot offer Bob these services either. Their son also told them that Bob needs to ask for help to care for Sue, but how can he get help when she resists?

7.4.2 Husband and Carer, Wife and Person with Dementia

As noted before, Sue often rejects her diagnosis of dementia; she does not want to be treated differently and she likes to continue going places on her own, and she denies the marriage. She acts upon this denial by going out when she likes to

without informing her husband about her whereabouts. Nevertheless, we need to keep in mind that she has a cognitive impairment, so another explanation might be that she forgets to inform her husband about her whereabouts. As explained in the example above, many others in society grant her this independence and will only undermine it when they think it might cause problems or danger for her; when they recognise the confusion as part of dementia they start treating her as a woman with dementia.

The situation creates challenges for Bob, although he likes to give Sue her independence and freedom: he knows her well and tells me she needs her independence. He is worried about her wellbeing; he never knows if she will make her way home on her own or will be brought back by the police or a taxi cab or whether he has to pick her up at a bus station – not even speaking about the scenario in which she might really get lost. When she does not make her own way home, Bob is often spoken to as if she is his responsibility; others will identify him as her husband and/or carer, but Sue does not acknowledge these identities of Bob.

It is painful for Bob not to be able to act on the roles that others in the family and broader society expect from him. His son expects him to care for his mum and to accept external help to do so. He is increasingly worried about the wandering behaviour of his mum. The council worker expects Bob to be the carer for Sue and make sure she stays safe, but in this case he is not even able to have Sue attend the appointment; even worse, the police have to call him to inform him where she is. This is a painful event for Bob that shows the social worker Bob's limitations in doing as expected. He shows his frustration with the situation and makes jokes to cope with his feelings.

7.5 'He Patted John on the Head and He Said, Oh I'm Really Sorry'

'It is not safe for John to drive but it is nice not to have to drive sometimes, to be honest. I am glad I can, otherwise I would be quite stuck. But, he is not a good passenger! Not a good passenger at all'. Diane explains: *'He would tell me when I should pull out and when I should pull back in, and all the rest of it, and then he is leaning over like this looking at the speedometer. You are exceeding the speed limit! One day our son was sitting in the back and he just went, "Dad that is the pot calling the kettle. She is not speeding" – because John used to get numerous speeding fines'*. She continues: '*If I go into town, it is a nightmare, because he remembers*

town as it was, without all the bus lanes. Once I got three bus lane offences on the same day. Because the thing is, when you get on to the bus lanes… you cannot flippin' get out of them, you know, you're stuck. So when we are in town he wants to direct me home and he gets angry when I do not follow it. I can deal with it, but when you've got this going on.

And he is manic about speed bumps. You know, I am doing about 10 miles an hour and queue of traffic behind me, and he, he's saying I'm hitting them too hard and that I will damage the tyres and I am thinking, they are more robust than you think. Once oh, I had go to the, to the tip to take some stuff and I am stuck waiting to pull out, there's somebody parked beside me. He just went, no, no, go, go, go!, right in me ear. I can drive round town, his shouting does not help. He even got us involved in incidents of road rage. He was making gestures out of the window. I am trying to say to him, look J. I am driving and I am not annoyed. If you are a woman driving alone in a big city, you do not take offence to these things of other drivers'.

She continues: *'But well last time somebody had done something that he perceived was not good at the petrol station. So, he had been making gestures at him all the time, and as I pulled out… this guy came up behind me and he pulled round in front of me, like this. And I thought, oh God. The guy got out and John's trying to get out, and he cannot work his seatbelt which is… that's a good thing in many respects. John said: "I'll get him, I'm going to punch him, I'm going to do this, this." Oh, it was a, "why are you waving two fingers at me?" John replied, "I am going to hit you, you did this, you know".*

So, I said: "Right, everybody stop. I am really sorry, and, and… I do not like doing it but, my husband has dementia, I am really sorry, he does not really, you know… what he is doing, basically". And this guy went, he patted John on the head and he said, "oh I am really sorry I did not know". And got back in his car and drove off. And I am sort of sat there thinking…'

Diane tells me how challenging it can be to go out with John in the car. He cannot drive any more but finds that hard to accept and equally does not seem to think that Diane drives well. Also, because John's recent habitus has become inaccessible he tries to direct Diane wrongly through town, which results in bus lane offences. One time their son was in the car and stood up for his mum but without referring to John's

health condition. He knows that is the reason but he prefers not to announce it in the situation.

Another time when John got them into an incident of road rage Diane felt the need to share John's identity as having dementia and the consequential difficulty he has in judging situations. She communicated this in popular language: *'He does not know what he is doing'*. Diane does not like to face up to this reality but felt like this was the only option she had as she wanted to prevent harm. This connects back to Chapter 5 on how the dementia diagnosis brings not only a stigma but also an acceptable reason to distinguish oneself from problematic and immoral behaviour, avoiding the responsibility for the behaviour.

When the other driver heard that John had dementia he apologised, showed understanding and even patted John on the head. On the one hand, this situation confirms the stigma of someone being ill and not having the ability to act independently, and on the other hand, it shows that the other driver has an understanding of dementia and it prevents John from getting hurt. But it also means Diane has to admit to being a wife of a person with dementia and has to embody the carer role in this situation. And she confirmed the stigma that John does not know what he is doing.

In this scene John is treated as someone with dementia only when his family finds it necessary to disclose his diagnosis, in this case for safety reasons. In other instances, his family tries to avoid this disclosure; earlier on in the scene the son stands up for his mother without referring to his dad's dementia although the dementia is clearly the reason his dad behaves the way he does in the car.

7.6 'She Never Needed to Go to the Hairdresser But I Think Nowadays She Does'

'Which reminds me, we have to go to the hairdresser's tomorrow. She only opens two days a week at the back end of the week. It is only two or three minutes away by car, you know, it is quite handy. Our daughter goes there as well and knows them well, when Mary wanted her hair to be done she said, "Oh I will go and see them down there, they will do your hair."' Dan continues: *'They are very good and they are quite good to me. They know me and we have a bit of a leg pull when we go. I will ask: "What time do you want me to pick her up, Wednesday morning?" She sees the*

funny side, you know, seeing this is only Monday. We have been going a while now and our daughter knew them before us. Mary did not used to go to the hairdressers most of her life. You used to do it yourself all the time, did you not?' 'Yeah', Mary replies. Dan explains: *'She never needed to go to the hairdresser but I think nowadays she does. They cut it when it needs it or when they think it needs it, do not they?' 'Yes'*, Mary confirms.

Mary always used to care about her looks, as explained in Chapter 4; nowadays she still does but she is no longer able to cut her hair herself. Her cognitive impairment disables her from acting upon this part of her habitus any longer. When Dan started to notice that Mary could not do it any more, he asked for the advice of their daughter who suggested she could visit the same hairdresser the daughter visits. Dan explains that it is important for him that the hairdresser knows them and understands their situation. He comments how he appreciates the small jokes they have that lighten the situation. Basically, he likes it when others in the community know about their situation – Mary's dementia and his caring role – without having to explicitly explain it and possibly being judged. The hairdresser's acknowledgement and respect for this viewpoint creates a hairdressing appointment that also serves as a small moment of respite for Dan while he knows Mary will be treated well and enjoy the visit. As shown in Photo 13A on the next page, she enjoys visiting the hairdresser.

Photo 13A Mary at the hairdresser's[29]

7.7 'And I Just Think, Oh, Just Be Quiet'

'We have got the privets there, but down the side of the house. Alan goes back, where the privets are, he puts his back to the privets and has the garden seat out, and nobody can see him, you know, walking past. Because everyone stops and chats, which is rather nice but it is sometimes you just want to be quiet, and you might talk to about ten people. You just think I will go out and read for an hour, and have a relax, and everybody asks how are you Alan, how are you Jane, you know, what are you doing, have you done, this-that, yeah, and I just think, oh, just be quiet. Because everybody is so friendly, and very good neighbours, we are not in each other's houses all the time but they are very supportive, especially since Alan has not been well they are very kind'. Alan adds: '*They have been putting out the bins, for collection'. 'Our neighbour Ben from two doors down does that',* Jane clarifies*. And with Esther next door I attend diet meetings every week. And Ana from three doors down took me to the hospital when Alan was admitted. Also, Cathy down the*

[29] Participants approved of publication

road works a cleaner for an elderly charity, and has given us information about the services they can offer'.

'Okay so people in the community help you out to keep doing the things you used to?' I ask. '*Yes, do you remember I told you Alan has not been able to join me to church for a while now, yesterday was Ash Wednesday which is important to us, and he was feeling a bit better. A friend suggested to pick us up and drop us off so we could attend church, it was great. The church is only down the road but he would not be able to walk there. Everyone at church was a bit shocked when they saw Alan, they did not recognise him. He has lost so much weight that he looks completely different, he has got loose skin around his tummy and even his face has changed'.* She pauses a couple of seconds then she continues: *'But it was nice, I even baked cake for the occasion, a lot of people told me I should not have put in all that effort but I enjoy it, baking is a stress relief'.* She starts smiling and concludes: *'Everyone liked the cakes'*. She continues: *'We know lots of people at church and like to help others. There is this one young boy in church whose mum is a single parent and his school was going on a trip to South America and he needed to raise money for it. It took us eighteen months but we helped him to raise the money. He still comes around to visit us and in particular Alan'. 'He is my friend',* Alan interrupts. '*Your friend, he plays several instruments and wants to do music at university, he used to say Alan knows absolutely everything about music – singers and who sang what, you know'.* She turns to Alan and says: *'He always says you are a power of information'. 'I am a stockpile. If it is good information, keep taking it. If not, throw it away',* Alan confirms.

The position and role of Jane and Alan in the community has shifted from being the ones who used to offer help and do tasks, like the decorating mentioned in the last chapter, towards being the couple that needs to receive help from others. They are grateful for all the help and support they receive from their neighbours, friends and family but also find it hard to accept that they cannot reciprocate this help the way they used to any more. Being able to help a boy at church to crowdfund and baking a cake for the church community have become even more important than before. It gives Jane and Alan the opportunity to embody their past identity and position in the community as a couple that others could rely on. Furthermore, the confrontation with their change in social identity and their change in wellbeing and loss of abilities

creates sadness; as such they do not always like to tell everyone how they are doing and which activities they cannot do any more. Their neighbours, on the other hand, like to know this information so they can offer them help and support.

It shows how Jane and Alan negotiate their social identity by offering help, accepting help and choosing to disclose information on what they can and cannot do any more. Even though the people in the neighbourhood discourage Jane from baking because they know she already has busy days caring for Alan, they enjoy the cakes. But mostly, they like to offer Jane and Alan help but also accept what they can still do themselves.

7.8 Roles, Identities and Positions in the Community

With the examples in this chapter I aimed to show how people with dementia and their partners stay involved in the community and continue their daily routines and or even create new ones, like Mary who started going to the hairdresser's only recently. In these interactions both past and more recent identities are enacted; when Sue first goes on the bus she is the independent women that can travel on her own; when she starts to be confused the driver recognises her dementia and acts upon her identity of being a person with dementia. Even though many bus drivers know Sue and are aware of her dementia, they will only treat her as a person with dementia when she seems confused and they are concerned about her safety and wellbeing in the particular situation.

For the person with dementia the situational shift in identity gives them the possibility to have their agency, but this is limited by the judgement of others in the situation who decide what is safe. For the caring spouse these situations can also create challenges: Bob is assumed to be responsible for Sue while he offers her independence and cannot rely on her to be home when agreed. In the case of Aaisha and Hamid, the difficulty it creates for Aaisha is that she does not feel acknowledged in her 'new role' as decision maker.

John still embodies his identity as being the driver, which is based on the part of his habitus he can still access which holds memories of driving and the roads. While he embodied this habitus he created a moment of road rage, and Diane saw no other possibility than to explain to the other driver that John has dementia. The man, whom they had never met before, patted John on the head and forgave him once he heard John had dementia. This is an example of how the stigma of

dementia, that people who have dementia do not know what they are doing, takes away John's responsibility for his behaviour (Smith 2006).

Dan finds it nice to know that the hairdresser knows about Mary's dementia without him explicitly having to explain it. She offers him respite care and Mary a hairstyle she likes. This matches with how Dan and Mary most like to cope with the dementia: they do not openly declare it and most of all like to be treated just like any other elderly person, but Dan does acknowledge that it is nice they know about the dementia. Jane and Alan also reflect on this duality; on the one hand they are grateful for the help their neighbours offer since Alan is not well, and on the other hand it creates a confrontation with the illness and their changed position in the community as merely receivers of support instead of those who offer others help.

The way people interact with the community is dynamic and changeable over time, just like the identities they act upon and that are acknowledged by others. Understanding the situationality of and plurality of having multiple identities that people act upon and or that are acknowledged can help us to understand better the complexity of the challenges that couples have to cope with in their day-to-day life, and how these challenges and coping strategies are situated in their social networks and community life.

Therefore, these insights could both help us to develop current discoursers in dementia care further like discourses on dementia and citizenship and dementia friendly communities. Moreover, these insights could help us to create tailored support for people with dementia and co-morbidities and their spouses in the community.

7.9 Summary

In this chapter I showed how an identity perspective can give us a better insight in the identities, roles and positions people hold in their community and social networks and how these are dynamic over time. People with dementia and their partners stay involved in the community and their social networks. They continue their daily routines and or even create new ones. An identity perspective shows the complexity, contextuality and dynamic nature of the identities, positions and roles of people with dementia and co-morbidities and their spouses in their community and social networks.

This understanding can help us to understand better which challenges they experience in their daily life and how they cope with them. Furthermore, these insights can help us to further develop the discourses on dementia and citizenship and dementia friendly communities. Ultimately, this understanding can help us to know how we can provide tailored support to cope with these challenges.

In the next chapter I will reflect on my role in the field and how I have selected this argument and the supporting narratives that have been presented in the previous chapters.

Chapter 8

‘I Will Treat You as If You Were My Daughter’

Reflecting on Ethnographic Research

It was a drowsy afternoon at the beginning of February, recruitment had not been easy so far, and my supervisors had given me another two weeks to proof my recruitment strategy. I was about to visit another dementia support group; the group was not much different from the groups I had visited so far. It took place in the communal area of a nursing home; the seven participants were sitting around a set of tables, which were covered in red tablecloths, having some tea and biscuits.

The leader of the activity welcomed me and asked me to take a seat. She introduced my project and told the group they were going to draw their own hand today. Everyone was happy to have a chat with me, and for some my story was a welcome interruption of the activity, but like before, most people found the project intense and were not sure whether they could commit to it. Bob and Sue expressed similar concerns at first, commenting how they did not like people to snoop around in their house. But after the chat they were happy to give me their contact details and I told them I would ring them in a week to ask whether they would like to take part. Bob commented that they would first go on holiday for a couple of weeks and that I should always ring around six, because the rest of the day they might be out. A couple of weeks after meeting them at the support group I rang them and they invited me for a cup of tea at their house.

Although we met at a dementia support group, both of them liked to keep that quiet. In fact, when we visited Bob’s cousin a couple of weeks later he made me tell him we met at a ‘community watch meeting’, as mentioned in Chapter 4. And when I asked them about their activities during the week they would leave out the dementia support group. Even before my first visit Bob asked me to not mention the dementia during my visit.

8.1 Introduction Chapter

In this chapter I will reflect on the process of doing research, being a researcher, building relationships with participants and deciding how to present the argument I have presented in the previous four chapters. First, I will give a background on

ethnography as a method and the different stages of fieldwork and how I have experienced them. Afterwards I will give a reflection on the choice of data to include in the thesis. The chapter will finish with a brief summary and a small introduction to the next chapter.

8.2 Background: Doing Ethnographic Research

Doing ethnographic research means putting yourself into the situation, event or place you are researching. In anthropological fieldwork you share daily life experiences with your participants by actively taking part in these experiences (van der Geest 2017). You would like to become part of the phenomenon in order to understand it from the inside out. This type of research is intense and requests a high level of reflexivity from whoever undertakes it. Stodulka (2015: 85) describes it as follows: 'Fieldwork is an intersubjective process of making sense of the sometimes messy field realities in which we position ourselves, to understand and explain other people's life worlds'. We as ethnographers are part of this process and our subjectivity influences how we interpret other subjectivities.

During my six months of fieldwork it was no different. I joined people in their daily life activities and wrote descriptions in my field notes, but also reflected on my own experiences and roles in the field in my personal diary. When I was trained as an anthropologist I learned about the typical phases and challenges that I would encounter in my fieldwork: entering the field, the insider/outsider dichotomy, negotiating access, building up rapport and consequently questioning my role and identity and, lastly, leaving the field. In this chapter I will reflect on the research from my perspective as an anthropologist, sharing with you how I encountered these 'classical' phases and challenges.

8.3 The Phases of Research

8.3.1 The Beginning

Each project starts with an idea and an opportunity. The ideas for research often develop over time and can be drawn from different experiences in life. So how did I find this opportunity to do a PhD project to understand better the daily life of people with dementia and co-morbidities and their spouses?

In general, I have always had an interest in how health conditions and illness shape and influence the experience of daily life. I was born with cerebral palsy, so I have a personal experience of living with a health condition and am aware of the multiple ways in which the condition has influenced and still influences different aspects of my life.

My interest in dementia in particular stems from my mother's work as a carer for people with dementia in a Dutch nursing home. Her experiences at work were part of our daily conversations over dinner. When I turned sixteen and was looking for a summer job my mum helped my sister and me to get jobs in the ward where she worked. I spent multiple summers working with people with dementia in the nursing home as a care assistant. The job and my mother's stories made me aware of the impact of dementia on the lives of both people living with dementia and everyone close to them. I wanted to support them. When I read about the PhD programme in Bradford I felt it would be an opportunity to support people with dementia and the people close to them.

Besides my interest in the field of dementia I have always had an interest in how society functions. Having been trained as both an anthropologist and a political scientist, I have an interest in looking at local/individual problems and phenomena, paying attention to how they present themselves in the broader society. Dementia has gained a place in the public arena and on the political agenda but also remains an individual experience which is often considered to be a private matter.

I have had a passion for ethnography for quite some time now. It developed when I did some ethnography in Ghana for my anthropology degree. The method gives you the opportunity to be part of the lives and experiences of the participants. I find it an inspirational method which not only makes you question the things you set out to question but also proves to be a process of development for the researcher as a person reflecting on your own norms, values and ways.

8.3.2 Entering the Field

Now that I have explained my motivation to apply for the studentship, I will reflect on the other phases of research that took place. I received three years of funding for which I am grateful, but in the grand scheme of things three years is only a small amount of time to do an ethnographic study. The classic anthropologists like Malinowski or Mead used to spend at least a year in the field (DeWalt and DeWalt

2010). When I was training to become an anthropologist I was told that you had to experience all the seasons at least once in the field to really understand the daily lives of the people and community you were studying. But the amount of time you would spend in the field is often at least equal to the amount of time you need to analyse the rich data you collect, and obviously you would need to prepare the fieldwork before you go and have to write up the thesis after the analysis. I knew from the start that a year of fieldwork would not be possible; there was simply no time.

At first, I wanted to plan two different fieldwork periods. Some anthropologists like to have several field visits and in the meantime they analyse the data from the first visit and then reflect on which topics they still needed to collect more data on during their second visit. It took me about a year to prepare for fieldwork: rewrite the research proposal, identify the study population, develop my theoretical framework, conduct a systematic search of the spouse care literature, read up on dementia literature in general, liaise with my expert by experience couple for advice on the topic, methods and recruitment for the study, and apply for ethics approval. Because of all the time I spent on this preparation I decided to limit the fieldwork period to from January 2017 to August 2017. In December 2016 I received the ethics approval for my study and I could start my recruitment – or as an anthropologist, I would call it time to enter the field.

In January 2017 I entered the field by contacting local dementia support and activity to groups to tell them about my project and ask them whether I could visit their groups to meet possible participants. The opening vignette describes one of these successful visits. Recruitment was difficult; although many groups were happy to invite me to their activities, not many of their participants were keen on taking part in my project. I knew it was not going to be easy, the expert by experience couple in my study had already expressed their concerns about the fact that I wanted to visit couples at home once a week for six months; the longitudinal character of the project might make people drop out. Besides, the time investment every week might be too much for couples who are already busy with medical appointments, support group visits and all the other activities they have. Furthermore, not everyone would feel comfortable letting a researcher into their house. Some people at the support groups voiced the same concerns and did not want to take part.

Because colleagues, experts by experience and my supervisors had raised their concerns about the study design and the possible difficulty in recruiting, I started doing voluntary work at a dementia support group about eight months before the actual recruitment. I was hoping it would offer me the opportunity to spend time getting to know people well beforehand, and perhaps this would make people feel more inclined to take part in my study. When the time came to recruit, only one couple of the group I volunteered with showed an interest in taking part. Unfortunately, the wife no longer had the ability to consent and I had to let them down because I could only include couples of whom both partners were still able to consent to taking part in the project. As an anthropologist I did not expect these concerns to be so apparent; when I did fieldwork in Ghana I used to just 'hang out' in town, talk to different people and be invited to their homes to have food or a chat or to view objects like traditional clothing.

When I reflect on my slight naivety concerning recruitment I can identify different things that became clear. This is research into the daily lives of people with an illness which carries a stigma; many people do not always want to disclose their health conditions and may feel a certain shame about it, as discussed in the previous chapters. Even people who visit support and activity groups experience this. If you found it difficult to accept a diagnosis or cope with its impact would you let a researcher come so close? Would you let someone into your house and tell them everything about your daily life? How easily do people in England invite others into their home anyway? Before I applied for the PhD position I had never been to England. I learned English in school and I knew England from popular culture: the English TV shows they broadcast in the Netherlands, the music, the literature we had to read in school. I naively assumed that it was probably not that different from my home country, the Netherlands, as it is also in Europe and pretty much a neighbouring country.

Another aspect I underestimated was how they would view me. As a researcher in health studies who likes to visit people at home, people tend to think you are a health care professional and depending on their previous experience with health care professionals and their views on services might feel hesitant to let you in to the house, as Bob explained in the opening vignette.

The third difficulty in recruitment was the short amount of time I had to recruit. I only had a month to recruit in order to keep six months left for the data collection.

Most of the support or activity groups would only run once a month, and only having the opportunity to meet people once before I asked them to consent did not always work. Still, I did not give up; at most groups there were at least a couple of people that asked me for an information leaflet and promised to contact me. After about two weeks I realised that most people did not call me back, so I decided to start asking for people's phone numbers when they showed interest and contact them myself after about a week. This strategy proved to be more fruitful.

In total I visited about fifteen support and activity groups in about a month's time. I found three couples by giving them an information leaflet and ringing them a week later to ask if they were still interested and or had additional questions. Three more couples showed interest in taking part, but when I called them they had to decline for health reasons or because of changes in the home care situation. For those living with dementia and co-morbidities, the health and care situation can change quickly and suddenly. I anticipated this, having identified it beforehand as a possible barrier to recruitment.

The other two couples that I recruited contacted me themselves after a friend or a family member who had attended one of the wellbeing cafés told them about the study and handed them a flyer. These two couples called me to tell me they were interested. I arranged a first visit with each couple. During the first visit I gave them an information sheet and introduced my project. A week after the first visit I called them again to see if they wanted to participate in the project. Both couples showed interest in being in the project, so I planned a further visit to sign the consent forms.

8.3.3 Building up Rapport and Negotiating Access

After five couples had signed the consent forms and gave me permission to visit them at home, the next step of the fieldwork started: gaining access to their daily life routine, the different spaces where this took place and the information about their routine I needed to understand their daily life better. It is worth noting that I commenced fieldwork with some couples while still visiting others to ask for consent to take part; not all five couples signed the consent forms at the same time.

The level of access I got to the daily lives of the couples was dependent on the level of rapport I built up with them (Harrington 2003). In anthropology we speak of an insider/outsider dichotomy, in which we as anthropologists are the outsiders who seek to gain access to the lives of our participants, the insiders. We often try to

identify events in our fieldwork that create a bridge from being the outsider into being acknowledged as 'new' insider (Pitts and Miller-Day 2007). A well-known such event in anthropological works is Cliffard Geertz's (1973) description of his attendance at a Balinese cockfight (DeWalt and DeWalt 2010).

In my study I cannot identify any pivotal moment in which I established an 'insider' position through one event. In two cases I do not think I reached this insider status – because the fieldwork came to an abrupt end when Alan was put on an end-of-life care pathway, and because I kept negotiating access with Aaisha and Hamid.

8.3.3.1 Aaisha and Hamid

In the case of Aaisha and Hamid, it felt like we kept negotiating my status as insider/outsider, and thus my access, over the duration of the fieldwork. Aaisha tried to get to know me and make sense of who I was by asking me questions about who I was and what type of life I was living. Since these questions repeated themselves often, I started to feel insecure about building rapport. Was I giving the answers they were expecting or hoping for?

Religion was very central in their life, so Aaisha used to ask me questions about my religious beliefs, as illustrated by the following fragment from my field notes: *'Do you go to church?'* I tell her I was raised Catholic but do not go to church any more. She says: *'You should go! God knows! You know God can be hard'.* She continues: *'You only pray once a week, we pray five times a day'*. She shakes her head showing she disapproves. I reply that Catholics usually pray every day, my grandmother does. She seems surprised and says she did not know. I did not dare to tell her that I officially left the church when I was eighteen and that I did not plan on re-joining.

Because I already felt like she was testing me and judging my way of life, I did not want to trigger more possible disapproval as it might damage our rapport and negatively influence my negotiation over access to their daily life. Whether or not and how to disclose your own religious beliefs in the field is a classic dilemma many fieldworkers face. Crapanzano (2010) discusses in his own reflections on fieldwork in South Africa how it was easier to disclose the fact he did not believe to his participants in South Africa than it had been during his previous fieldwork in Morocco. He emphasises how much of this dilemma is influenced by our own

assumptions about the expectations and ideas of the people we disclose this information to.

Reflecting on the situation now, I wonder if I should have explained to her that I was not religious any more. A further explanation could have led to further disapproval, as I feared, but it could also have offered Aaisha more in-depth information on why I was living my life the way I was. Perhaps it could have taken away some of her mistrust. During a later visit she commented: *'I do not like Christianity, Christian religions, old religions. They are not honest, they do not follow the prophet. They do not do as our prophet said, the women are badly behaved and they eat pork. There is one rule which is do as the prophet says, they do not follow that rule'.* Aaisha would possibly always have viewed me as 'the outsider' as I did not follow the prophet she follows. Still, these are just assumptions I make about how she might have had responded if I had disclosed the information.

Nevertheless, the ongoing negotiation over access eventually gave me important information on her identity and position in social relationships, for example her difficulty trusting health care professionals and services because they did not seem to take her seriously, as illustrated in the previous chapter. She might have viewed me as another health care worker offering services and making appointments which I would not always follow up.

8.3.3.2 Dan and Mary

With Dan and Mary, rapport built up gradually; it started with them announcing how their son had also done a PhD. They knew how difficult it could be and were happy to help me out. In the moments in which my experiences showed some resemblance to theirs or when they knew others with similar experiences, our rapport was strengthened; for example, when I told them I understood how it felt not being able to do certain activities that friends can do because of health conditions. I have experienced similar situations because of my cerebral palsy. Or when I told them my grandmother was their age it helped to build rapport. Eventually Dan viewed me as a friend.

In anthropology it is well known that you should learn to 'walk the walk' and 'talk the talk' to be more easily accepted and trusted by the population you are researching (DeWalt and DeWalt 2010). In this case, the examples I gave that

showed resemblance between our very different lives were comparable to understanding their ‘walk’ and ‘talk’.

8.3.3.3 Bob and Sue

Building up rapport with Bob and Sue was similar, although they felt a bit suspicious about taking part in the project at first. As described in the opening vignette, they did not want anyone in their house/life who would just come around to investigate their life. After a chat in which I explained the project, they were happy to invite me to their house, and after a couple of visits they seemed to really enjoy taking part in the project. At a certain point Bob said: *‘I will treat you as if you were my daughter’.*

In anthropological research this is a well-known phenomenon that many anthropologists experience. When trained as anthropologist I was advised to be careful about fictive kinship relationships and to only accept them when I could fulfil the responsibilities that are connected to such status (Cassell 2016), as mentioned in Chapter 3. I told Bob and Sue I was not comfortable with that role as I am still the researcher and I will not be around that much. But overall this comment does reflect the level of rapport we developed.

8.3.3.4 Diane and John

Diane and John viewed me as the researcher and when I would visit we would spend the visit at the kitchen table talking about topics on my topic list. I met them when the singing group they are part of visited the university for a performance. Like many others in the choir, they were members of the expert by experience panel of the university. This is a PPI (patients and public involvement) group of the university which is focussed on people with dementia, their family carers and formal carers. They meet regularly at the university and do several things: they teach, assess or evaluate the courses on dementia that the university provides. They advise on current or future research studies of the university. They contribute to practice-development initiatives. They promote public awareness and challenge stereotypes. And they try to develop dementia-friendly communities (UniversityofBradford 2018).

The better I got to know them, the more they told me about their daily life and the latest changes and challenges in their life, but they did not invite me to do participant observation on any of their daily life experiences outside of the home.

They visited many support and activity groups and Diane was motivated to contribute to research into dementia care to make the situation better for other people living with dementia or caring for someone with dementia. They also took part in an interview study by a colleague of mine, but as this was only one interview it did not interfere with my fieldwork.

Beard (2016) describes in her ethnography on memory clinics that memory clinics encouraged people to take part in research and that many of the visitors to the clinic decided they would like to be involved in research to help others. Perhaps John and Diane's involvement in many support and activity groups and their involvement in the expert by experience group of the university motivated them to take part in research because in these groups they often discuss what could be better for people with dementia and their family carers. This might have influenced the way they structured and behaved on my house visits.

Although the roles of researcher and participant seemed very clear in this case, we did get to know each other well and when I visited for the last time and said goodbye Diane and John walked with me into the front garden, told me they enjoyed my visits and asked me if we could stay in touch and perhaps go for a coffee sometime.

8.3.3.5 Jane and Alan

Rapport building with Jane and Alan was abruptly disrupted when after three months of visits Jane rang me one evening to tell me some sad news. Alan's health had been declining rapidly over the previous months, he had lost a lot of weight and had been admitted to hospital multiple times. The day of the phone call the doctor had diagnosed Alan with yet another chest infection. He had had multiple chest infections over the last couple of months, and because of his frailty and other health conditions like COPD, heart condition, diabetes, ulcers and dementia his body was struggling to fight the infection. The GP had told them that Alan would probably not die because of dementia but of an infection like this one.

Alan had entered a palliative care pathway that day. When Jane rang me, she seemed overwhelmed; she did not anticipate this happening and asked to cancel my next visit. When I rang them the next week to ask how they were doing, she told me that she still felt overwhelmed and was tired; medical professionals were entering the

house multiple times a day and she experienced it as busy. Because she felt so overwhelmed and thought it was already busy in the house she decided to withdraw them from the study. They had provided consent to use the data that I collected in the time they participated.

8.3.4 Insider/Outsider

The process of creating rapport with the couples was different with each of them (DeWalt and DeWalt 2010), but what they had in common was the curiosity and creation of a role and status in their life usually based on a comparison with their expectations and cultural framework, ethos and past experiences. Either I stayed the outsider because during the process of comparison my way of life did not fit their cultural framework, or they would find similarities and recognition, confirming my role of researcher or eventually viewing me as a friend or even a family member.

The type of relationship influenced the type of data I collected. The couples who perceived me as a friend or even a family member offered me more opportunities to do more participant observation and showed me more of their daily lives than did the families that viewed me as either an outsider or a researcher. Nevertheless, I am grateful for the insight all of the couples gave me into their daily lives and experiences. After six months of fieldwork in which the couples shared with me many aspects of their daily lives it was time to leave the field.

8.3.5 Leaving the Field

Chapter 4 starts with a vignette in which I describe the visit in which Dan tells me that Mary passed away. This visit to Dan's house just took place in March. I had last seen Dan and Mary at the end of August when I finished the regular weekly visits and left the field; Mary passed away in October. Dan apologised to me for not letting me know earlier, but he had had a difficult time coping with the loss of Mary. At the time she passed away he could not find the card with my contact information. In the meantime, I had asked myself if something might have happened to them. I sent them a new year's card but did not receive a reply, which felt a bit out of character. Instead of contacting them at the time, I decided to leave it up to them to contact me when they wanted to. Dan rang me in March and invited me for a cup of tea so he could tell me the whole story.

When I was there he said it was important to him to tell me; this was valuable information for the research project. He also told me how much he appreciated being in the study. At the start he was a bit sceptical about it as he did not necessarily want to share so much information with a researcher. But in the end, he felt it gave him the space to share stories with an 'expert'. When he told me the story about Mary passing away he said: *'I can tell you all of this and show emotion because I know you are an 'expert', normally I only share this with close family'.* He continued: *'You must have come across situations like this with other couples as well'.* Eventually he concluded by saying that he appreciated our friendship and would like to stay in touch. I suggested exchanging e-mail addresses; his son and daughter had given him a laptop for his birthday and enrolled him in a computer course, encouraging him to go on with life and find new activities to do. By exchanging e-mail addresses, he could practise using the laptop and we were able to continue the friendship even when I would not be able to visit regularly.

I do not consider myself an expert when it comes to dealing with emotions of loss and grief, but I was happy I had been able to develop a bond with Dan and Mary which had allowed them to share difficult times and gain a sense of support. People deal with grief in diverse ways, and I told Dan he did not have to apologise for not letting me know earlier; he told me when he was ready.

This event shows how I never literally left the field. I stopped visiting the couples weekly and I drew my data collection to a close, but the relationships I built up with most couples continued. This is another aspect of anthropological fieldwork: usually you build up a relationship with people in a community and/or field that you stay in touch with and sometimes even revisit once or multiple times over the years (DeWalt and DeWalt 2010). Because of the age and the health conditions of the participants, revisiting the field in a couple of years' time might be impossible, but still I find it important to continue the relationship I have built with the couples who would like to stay in touch as well.

Not literally leaving the field was also influenced by the fact that I had conducted my fieldwork in the city where I lived and a neighbouring city. I did not simply move back to the Netherlands as I had done after the previous fieldwork I did in Ghana for my bachelor degree. Distance from the field can be fruitful as it is easier to reflect on the data and the experience of fieldwork when you can detach yourself from it slightly. When I left the UK for two and a half months in April to visit the

medical anthropology research group at the department of social and cultural anthropology at the Freie Universität in Berlin I experienced how valuable it can be to physically leave the field for a while. Spending some time in a different environment made it easier for me to reflect on the project and decide what the main message of the thesis should be. Being away from the field boosted my reflexivity and my ability to process the outcomes of the data analysis. In fact, I wrote the first full draft of the thesis during my stay in Berlin.

Although I never completely left the field I did design a strategy to leave, as already explained in Chapter 3: when the end of the data collection period approached, I reminded the participants of the fact that only a couple of visits were left. At the end of the project I printed all the photo diary pictures for every couple and bought them a gift card of 15 pounds together with a thank-you card as a type of reciprocity and to provide them an object that symbolised the end of the fieldwork phase. Reciprocity is an important part of establishing rapport and continuing it (DeWalt and DeWalt 2010).

I either mailed them the package or brought it in a visit, having phoned them first to find out what they preferred. In the card I expressed my thanks for their participation and gave them my personal phone number and address so they could stay in touch if they wished. In the months after the project, three couples initially showed interest in staying in touch. Two of them either messaged me or rang me sometimes and the third couple invited me for a meal. I left the initiative to stay in touch with the couples, but sent all of them a happy new year card after the holidays out of courtesy. I still speak to Bob and Sue and Dan approximately once a month, and Diane and I send each other text messages once in a while to let each other know how we are doing. The other two couples haven't contacted me since the fieldwork.

8.4 Emotions in the Field

All anthropologists experience emotions in the field and it is important to reflect on them: emotions influence the interpretation of your data. In the 1960s Malinowski's personal diary with reflections on his fieldwork, including his description of feelings of loneliness, anxieties and frustrations, was published, and since end of the seventies anthropologists like Rabinow (1977) with his Reflexions on fieldwork in Morocco have written critical reflections on their experiences in the field, including reflections

on the boundaries between private life and research and certain emotions (Davies and Spencer 2010; van der Geest 2017). Fieldwork often creates a confrontation with yourself. Feelings of loneliness and homesickness are generally shared emotions among fieldworkers (DeWalt and DeWalt 2010). I knew this from both my training and my previous fieldwork in Ghana; still, the type of confrontations and accompanying emotions you will be challenged by are never predictable.

I had not anticipated the feelings of loneliness and home sickness I experienced in the field. Working so close with families confronted me with being alone in a foreign country, being single and without family around. I also did not think I would be reminded of my decision to leave the church; my opinion on it has not changed but when I was in the field I did not dare to disclose this information. I would either say I did not go to church any more or I would not disclose any information about my religious beliefs. Three couples in my study got a sense of support from their religious beliefs and I did not want to make them feel like I would not acknowledge this type of support.

Furthermore, some anthropologists even suggest that reflecting on and acknowledging the role of our emotions in the construction of data could help us to gain a deeper understanding of the data, using emotions as part of gaining knowledge (Davies and Spencer 2010; Stodulka 2015). And emotions may influence our decisions on how we engage with our participants and build up rapport (Stodulka 2015). I will now reflect on different emotions and emotional events that I experienced during fieldwork.

8.4.1 Participants Passing Away

Although I knew the participants in my study were all old and living with dementia and co-morbidities, I did not expect that any of them would pass away during or soon after my fieldwork. I had noticed how Alan had lost weight every time I visited them and I did worry about his wellbeing, but I did not expect his health would decline as fast as it did. Even though I had only known them for three months, I felt sad about not having the opportunity to say goodbye. Because they withdrew from my study over the phone and there was no opportunity to pay them a last visit, I decided I would contact Jane a couple of months later to ask her how she was doing.

When Jane and Alan left the study, I decided I would not try to recruit another couple. I would not have had the time to spend another six months with a new

couple and the three months of fieldwork had already provided me with much rich data; in combination with the data of the other four couples I have sufficient data to answer my research question.

Just after Jane and Alan had left the study, I send them a card to wish them strength in these difficult times. A couple of months later I rang Jane to ask how she was doing. I had expected her to tell me that Alan had passed away and that the last couple of months had been hard. Instead she told me that Alan had made a recovery while he was on the palliative care pathway. She told me that he had gained some weight again and that a physiotherapist paid them weekly visits to help Alan to build up some strength again.

Not long after the weekly visits ended, Mary passed away, but I only found out months later when Dan contacted me to tell me the news. On the one hand I felt a bit sad that I did not have the opportunity to attend her funeral, but on the other hand I realised that if it had taken Dan so long to feel ready to share the news with me it must have been a very hard time for him. When someone is overwhelmed by emotions a researcher is not the first person you will call to invite to a funeral. Besides, I do not know how public funerals are in England. In the Netherlands, funerals are mostly partly public and partly a family occasion. Most of the time everyone is welcome to attend the funeral but the activities afterwards are usually only for family and close friends.

These experiences of Jane and Alan show how co-morbidities can create disruptions abruptly and sometimes the body still finds enough energy to continue. It can all be an emotional rollercoaster and how it will progress is difficult to predict. After the last phone call, I have not heard from them any more so I do not know how they are doing at the moment. I experienced sadness about participants passing away, but having been able to call Jane a couple of months later, send Jane and Alan a card and being invited for a coffee by Dan so he could tell me about Mary passing away, provided me with some closure.

8.4.2 Uncomfortable Situations

Being part of the phenomenon you study is not always easy; sometimes I found myself feeling a bit uncomfortable with the situation I found myself in. A good example of is was the returning arguments Bob and Sue had about being married. When an argument like that started, I used to stop the recording and wait till they

changed the subject themselves. Once I tried to calm the situation down by asking Sue about some of the positive aspects of living with Bob, as illustrated by the following fragment:

'The dinner is nice', Sue answers. I ask her if it is not nice that he always takes her for drives out but she only says sometimes, or it is not bad. I could tell Bob was hurt. I hoped she would make some positive comments but this did not happen. After this event I decided to not interfere any more when the topic returns again.

Another difficulty was deciding what to do when participants became emotional. I found myself having to balancing between the positions of researcher and friend. When a friend of mine would become upset and start crying I would offer to give him or her a hug, but when being the researcher this might not be considered professional. In most situations when a participant would become emotional I would pause the conversation for a bit and ask them if they would like to end the conversation or change the topic. Sometimes they told me they would prefer to talk about it a bit more and I would give them space to show their emotions and continue their story. On one occasion I gave a participant a hug. Dan told me about the day Mary had passed away and tears kept rolling down his face; even though it was really difficult for him to tell the story he insisted on telling me the whole story. When he told me, the weekly visits had ended and he reflected on the friendship we had built up. In this situation it felt appropriate to treat him as a friend and offer him a hug. This scene is presented as the opening vignette of Chapter 4.

8.4.3 Loneliness, Stress and Homesickness

When I did a presentation at the University of Witten in Germany one of the researchers there asked me: 'How have you been able to complete this type of study in three years including six months of fieldwork with five couples? Was there someone at home to cook your dinner when you came home? Did you even have time to see family and friends during those months?' These questions made me realise how intense the fieldwork was.

I constantly felt that I was on a time constraint and I spent full days paying visits, writing fieldnotes, writing a personal diary and keeping a methodology diary. Besides all these fieldwork activities I also prepared my transfer report and had to

attend meetings and activities of the DTC. It was a very busy time and sometimes I wonder if I might have worked a bit too hard. Approaching the end of the fieldwork I felt exhausted and I planned to take two weeks off in August to go on holiday and do the last couple of visits after my holiday. I needed some time to take some distance from the field. If I had had more time to conduct the project, I would probably have preferred to do the fieldwork in different shifts of a couple of months, leaving time in between to do some preliminary analysis and reflection and work more balanced hours before going into the field again, where I would be working almost all the time. When you are in the field almost everything you do becomes part of the fieldwork, which together with an active self-awareness and continuous reflecting becomes exhausting work.

Returning to the questions above – no, I did not have someone who cooked me dinner; in fact, I lived on my own. Doing research with couples and always returning to an empty house sometimes felt strange and lonely. Not only did I live alone at the time, I also barely had time to visit family or friends. During my fieldwork my grandfather in the Netherlands passed away and I made time to visit my family, but still I felt some guilt about not having been able to spend much time with them over the previous months since I started the PhD. I had a special bond with him: growing up, all my grandparents lived close and I used to see them weekly, sometimes even daily. Building up close relations with the couples in my study made me think about the close relationship I have with my grandmother and used to have with my other grandparents.

8.5 Expert, Friend, Researcher

Sometimes the lines between the different roles and identities I had throughout the fieldwork blurred. I did not want to be viewed as a medical professional or expert, I wanted to learn from the participants about their way of life and how they coped. Still, I sometimes found myself in a situation in which I was referred to as being the expert. Dan asked me questions about the symptoms of dementia Mary had, whether they were typical, and he asked me if the advice a local charity gave him was right. Diane asked me for my opinion on when the right time would be to move John into care, and Bob asked me my opinion on several things, like Sue's wandering and whether they could still go on holiday together. In all cases when participants asked for advice I would give them some general information and tell

them where they could get better information. Sometimes I would also express my opinion but I would then explicitly state that this was my opinion and that I was unable to provide them with advice.

8.6 Choice of Argument for Thesis

Not only would I like to reflect on my position in the field and role as researcher, but also on the decision I made to present the data I presented in the thesis. As explained in the methodology chapter, I analysed the data using framework analysis, which allowed me to use both a deductive and inductive approach. Originally when I set out to do the project I expected to focus on the structural factors that differentiate my participants, such as their socio-economic background, gender, ethnicity and the diversity of their co-morbidities, but when in the field time was too short to reflect on all, guided by the themes identified in the systematic synthesis on spouse care, I decided to focus on the relationship of the couple and their individual identities.

All narratives and events that are represented in the thesis were selected because they illustrate how habitus and identity are represented in different aspects of the daily life of the couples and influence the way they cope with the challenges they face and create disruption and continuity. Because identity turned out to be the main theme in the data and I had to work on a tight time schedule, I decided to mainly focus on Bourdieu's concept of habitus, a common sense and the body. I did not elaborately discuss the other concepts in his theory of practice. As the structural factors named before do influence identity and were indirectly represented in the data, other concepts from Bourdieu's theory of practice, such as cultural capital, social capital and economic capital, may also offer a theoretical lens to further understand the dichotomy between the diverse and uniqueness and shared aspects of living with these health conditions, and provide further contextual insight to understand the identity approach to look at the lived experience better. This could be an idea for future research.

8.7 Summary

In this chapter I have reflected on the process in which the project was designed and carried out: the choice of the topic, the practical constraints, the fieldwork experience, my role in the field, the personal experiences in the field and finally my decision to present the argument I have presented in the previous four chapters.

Now that I have presented the argument of the thesis and reflected on the process and my role as researcher it is time to draw conclusions and present possible implications for care.

Chapter 9

Discussion, Conclusion and Implications for Care

9.1 Introduction

In this chapter I will discuss how the results presented in chapter 4 to 7 connect to the current knowledge on the daily life experience of co-habiting spouses of whom one has got dementia and co-morbidities and the partner is the primary carer. Furthermore, I will reflect on how the data has answered the research questions and fulfilled the aims and objectives of the study. Afterwards, I will reflect on the used methods and methodology, and the strengths and limitations of the study. Next I will provide suggestions for future research possibilities. Afterwards, I will present implications for policy and practice. Finally, I will conclude how this project has contributed to the current knowledge in dementia care research and how we could deepen our understanding in future research into the lived experience.

9.2 Discussion

Existing knowledge on the daily life experience of spouses of whom one has dementia and the partner is the carer and who live together in the community focusses on the role of relationship of the couple and the identities of both spouses, as described in chapter 2. The literature shows how all couples have to cope with changes in their daily lives due to the health conditions and how these changes can create disruption in their daily life routine and relationship. Important changes that have been identified are changes in the role division between the couple, changes in the ability of the person with dementia to do certain tasks and activities, a difficulty in communication between the couple, a change in how one perceives the future and new tasks and roles that need to be fulfilled, such as the caring role, health management and becoming the mediator for your spouses in social interaction (Murry et al.1999; Jansson et al. 2001; Clare 2002; Paun 2003; Vikström et al. 2005; Brown et al. 2007; Daniels et al. 2007; Hellström et al. 2007; Vikström et al. 2008; Walters et al. 2010; Beard et al. 2012; Botsford et al. 2012; Boyle 2013; Boyle 2014; Eriksson et al. 2013; Shim et al 2013; Bergman et al. 2016). These changes also bring other challenges in daily life, including an imbalance in the fulfilment of the

needs of the two spouses (Jannson et al. 2001; Vikström et al 2008; Walters et al. 2010).

These changes and challenges create disruption in the daily life and relationship of the couple. Couples cope with this disruption by creating continuity in their daily life, by continuing to do activities together and giving meaning to the changes. Important motivations and meanings that couple give to these changes are related to a commitment to caring for each other in the relationship and their identity as a husband or wife. Identity influences the experience of these changes: the meaning spouses give to these changes and coping strategies they use. The focus on identity in the current literature is mainly on gender and cultural identity as identities that influence these experiences and how people cope with them and the meaning they ascribe to them. People have many more identities besides their cultural and gender identities.

Everyone owns multiple identities and depending on the context one or a couple of these identities will be relevant and others will acknowledge those identities and act upon them (Burke and Stetts 2009). This is well illustrated in the vignette of Bob and Sue in chapter 6 when a council worker comes to visit their house. The council worker identifies and treats Bob as the carer while later on in the day both the police and the bus driver identify and treat Bob as the husband of Sue. Bob is both the carer and the husband, depending on the context he will identify and act up on one of these identities.

While couples experience many changes including in their health, abilities and daily life routines, they go through a relationship redefinition process; the way they give meaning to the changes and the coping strategies they use will influence the outcome of this process. Couples go through different phases, starting with ‘sustaining couplehood’, followed by ‘maintaining involvement’ and eventually ‘moving on’. In the last phase, a couple chooses whether they would like to continue as a couple ‘we’ or continue as two individuals ‘I’ (Hellström et al. 2007; Walters et al. 2010; Beard et al. 2012).

Even though the major changes in the daily life experience of these couples have been identified and processes in which different aspects of daily life that would influence these changes, such as identity, have been described, there is not much understanding of how these processes work and how these aspects of daily life are interrelated, context bound and situational. Furthermore, some other factors that

could influence these processes, including co-morbidities, have been neglected. Studies so far have been mainly explorative; there is a need for more explanatory research into the identified changes and described processes.

In this thesis I have presented a holistic explanatory research approach that seeks to create a deeper understanding of these changes and processes, especially on the topics of the daily routine, relationship and identity, taking into consideration the influence of co-morbidities. The main research question was:
How do dementia and co-morbidities influence the daily life experience of co-habiting spouses in the community in England? The other two research questions focussed on how dementia and co-morbidities influence the daily routine, relationship and identity of spouses in the community of whom one has dementia and co-morbidities and the partner is the carer. The research questions focussed on the main themes that were identified in the systematic synthesis in Chapter 2: daily life experience, identity, relationship and dementia. And on co-morbidities as this topic had not been researched in this context yet.

I used interpretative ethnography(Boeije et al. 2009) and offered an identity perspective based on Bourdieu's dialectic relationship between the body, habitus, body and physical environment (1977; Bourdieu 1990) and Kontos's (2004; 2005; 2006; 2013) concept of embodied selfhood, further developed by adding identity theory as described by Burke and Stetts (2009). Using this perspective, I gained a deeper understanding of the changes in daily life and the relationship of the couple by focussing on both individuals, their individual identities, bodies and habitus but also taking into consideration how they were related to each other in a relationship looking at their common sense and the environment in which they both find themselves and interact with each other.

This perspective has shown how dynamic, context bound and situational the experiences of the couples, the changes they experience, the meaning they give to them and coping strategies they use are. It also showed how dementia in combination with co-morbidities created more changes and more complex care situations that could potentially create more challenges. This was clearly illustrated by the example of a daily routine of Dan and Mary's, in which the combination of Mary's loss of mobility and dementia made her unable to even go up the stairs on her own. And in the example of Sue who is waiting for the bus wearing the wrong

glasses, which could enhance her confusion and make it more likely that she takes the wrong bus.

Furthermore, the perspective revealed the importance of identity in these experiences. Just like someone has multiple identities that are changeable over time and acts upon different ones in different situations, one can make sense of the daily life experiences with dementia and co-morbidities differently over time and in different situations. This was shown clearly in Chapter 5 with examples of how people decided in which context they would accept or reject their diagnosis of dementia.

Although the way people make sense of these changes and respond to them is changeable over time and situations, it does rely heavily on their habitus. As shown in Chapter 4, couples try to create continuity in their daily life when they experience disruptions by using coping strategies that are informed by their habitus. A good example is how they adapt activities in their daily routine so they can continue them, rely on religion to understand the changes, and/or change the meaning of well-established routines like going for reiki and reflexology to cope with the health conditions. Nevertheless, sometimes the current habitus has to be changed to cope with the situation and create continuity, as when Bob and Sue normalise Sue's incontinence to create continuity.

The way people make sense of these changes does not rely only on their individual habitus; these habituses are influenced by the common sense of the group they belong to. One of these groups is the society you belong to; ideas about dementia in society do influence the way people make sense of their health conditions and how they give meaning to the experienced disruptions and cope with them. In Chapter 5 I showed how the stigma of dementia in society that says 'People with dementia do not know what they are doing' influences when people accept or deny their dementia and make sense of their health condition. Sometimes spouses would accept the dementia to make sense of changes and behaviour that seems 'abnormal' by ascribing it to the dementia (Smith 2006). This created continuity as they did not have to blame themselves or their spouses for disruptive or 'abnormal' behaviour. In other situations, the couples would reject the dementia as they do not want to be viewed as different and/or incapable of knowing what they are doing, Sue described it: 'I am not crazy'.

The acceptance, rejection or ignorance of the dementia diagnosis by spouses

influenced their access to help, support and knowledge on the dementia. Sue's rejection of her diagnosis meant she is not willing to accept any support and refuses to take medication. This also influences the support her husband can get. If Sue refuses to go to a day centre and/or go into respite care, it means that her husband cannot get a break from his care role. Dan and Mary's avoidance of Mary's diagnosis meant that for a long time Dan did not access the available knowledge on caring for someone with dementia. Furthermore, the avoidance eventually created more disruption in their relationship and daily life, as he could not understand some of the changes they went through, like Mary's inability to remember that they had lived in the same house for forty years and it was still their home.

Even when a couple did accept the diagnosis, they experienced changes and disruptions in their relationship; as the literature describes there is a redefinition process in the couples' relationship. Just like in the existing literature I found that couples experience different changes in their daily life and relationship, like a change in role patterns, change in communication, the carer who becomes the mediator of social relationships and the imbalance in fulfilment of needs. An example from my data of the change in role patterns is Aaisha who becomes the decision maker in the relationship. An example of the difficulty in communication is when Sue accuses Bob of not listening to her. An example of the carer as mediator in social relationship is Dan who needs to initiate a conversation between Mary and friends. And an example of the imbalance of the fulfilment of needs of both spouses is the case of John and Diane in which Diane is advised by a social worker to move John into care because she needs to think about her own health.

In the existing literature these changes and challenges are described as being part of the redefinition process of the relationship of the couple as it moves through different phases. In this thesis I have shown that there is a redefinition process in the relationship, but that it does not move in different phases and end with 'moving on' when a couple decides whether they will continue as a couple or move on as individuals. Instead, they would find themselves holding on to being a couple in some situations and contexts, while they prefer to be viewed as individuals in other situations and contexts. All spouses in this project liked to continue things on their own: Sue would go on the bus on her own, Bob liked to visit the pub on Friday evening, Dan went to his men's forum meeting, Hamid went to the mosque to pray and Aaisha liked to keep attending the women's group. In other contexts, they

preferred to be viewed as a couple and do things together: Jane and Alan liked to go to mass together, Dan and Mary liked to go on drives out together and Diane and John used to visit a singing group together.

Even though all couples hold on to their shared identity as a couple in some contexts, this shared identity was challenged by the dementia and co-morbidities. In Chapter 6 I showed how a loss of important shared memories, like remembering being married, having a son together or having lost some family members, can create a loss of common sense and challenges the identities of both spouses as husband and wife. It challenged the mutual recognition of identity because the inaccessibility of the habitus of the person with dementia that created this loss of a common sense also created unexpected behaviour that did not match their identity. Their body would embody the part of the habitus that was accessible, which left out important memories like having lived in a house for many years. A clear example of this can be found in Chapter 6, where Mary cannot remember that the home they have lived in for many years is their house and keeps requesting Dan to go home. This is a particularly difficult situation for Dan because having a home together is an important part of their marriage; this challenges both their identities. How can his wife not remember that they have shared this house for so many years? That they have bought it together, made it a home together? The unexpected behaviour of Mary not recognising the house created a problem in the identity verification process of the couple.

Not only does the habitus play an important role in the challenge of the shared identity of the couple, but the body also plays a key role. As explained in the example above, the body embodied the part of the habitus that was accessible to Mary, which meant she did not remember living in the house, which created unexpected behaviour. Sometimes a body is not able to act upon the habitus because of cognitive impairment and/or the loss of other abilities because of the co-morbidities: Alan's body cannot embody his identity as a 'manual worker' anymore and Hamid is no longer able to fulfil his tasks as head of the community centre. The loss of these abilities challenges the identity verification process as well. When someone is no longer able to behave the way that is expected according to their identity and habitus, others in the situation will find it hard to recognise their identity and confirm it. This will also make it more difficult for spouses to confirm each other's identity as spouses because a spouse with dementia and co-morbidities might not be

able any more to embody the identity, habitus, of the spouse he or she used to be in the relationship.

Another factor that influences this identity verification process is the environment. Different environments create different expectations of behaviour. As shown in the example of Mary who does not recognise the house as her home any more, it can create a challenge in identity verification and a challenge for the relationship when someone is no longer able to behave as expected according to the environment.

These findings challenge some of the current ideas within dementia care and research. First of all, the examples of the spouses of whom part of their habitus has become inaccessible, like Sue and Mary, and who act upon the part of the habitus that is still accessible – Sue who denies the marriage and starts sleeping in a different bedroom and Mary who does not recognise the house and asks to go home – challenge the findings of Kontos (2004; 2005; 2006; 2013) that people with dementia may not be able to remember some things but still embody them and behave accordingly to the circumstances. This might be the case sometimes, as in the example she used of a woman who did not remember she could sew but when she was handed a needle and thread started sewing again. But it is not the case in all cases, as the examples in this thesis show.

Furthermore, these outcomes challenge dominant ideas in dementia care and policy on the importance of ageing in place for people with dementia. According to these ideas the familiar home environment would serve to reassure and reduce confusion for people with dementia (NHS 2015). In this thesis I showed how the home environment is not as familiar to people with dementia as assumed: Mary does not recognise the house she has lived in for over forty years as her home anymore and cannot always find the way back to the bedroom when she goes to the bathroom in the night. Hamid cannot find the bathroom in the garage anymore and needs instructions to find the upstairs bathroom although he has lived in the same house for almost fifty years. John seems to think the house is a care facility and asks Diane if she should not be working and takes his toiletry bag with him to the bedroom at night. To these spouses the home environment is not familiar anymore and creates confusion instead of reducing it. Also, these situations create tension in the relationships of the couples as they challenge the identity verification process as mentioned above.

We should rethink this assumption of the home environment which reduces confusion, keeping in mind that what is familiar and not familiar is changeable and difficult to predict. For example, at one moment Mary does not remember that her mum has passed away but does remember when Dan shows her the gravestone, and she does not remember the house they live in till Dan shows her that someone else lives in their old house. Still when they arrive at their current house she does not recognise it. This shows clearly how what is familiar and unfamiliar is changeable over time; even in the space of an afternoon this can change multiple times, creating stress and confusion. Therefore, policy should take into account that a familiar environment to someone with dementia is changeable. People should be advised that the home environment might not always reduce confusion and could even increase it in some cases. Policy should take into account that focussing on living at home as long as possible in order to make people feel less anxious and more at ease might not be the right policy for everyone with dementia.

The home environment is not the only environment in which the identities of the spouses are challenged or confirmed. In Chapter 7 I showed how assumptions about dementia in society, the family and the behaviour of the couples in the community and their family influence their social identity and create disruption or continuity in their daily routine. A clear example of this is Sue who always used to take the bus on her own to visit her home town; now that she has dementia she still goes on the bus on her own. The bus drivers still treat her like every other passenger who can go places on their own, but when they recognise ‘abnormal’ behaviour which they associate with confusion or possibly dangerous situations they treat her as a person with dementia. They often let Sue go on the bus on her own but call the police or her husband to pick her up when she acts confused. Identity is changeable multiple times a day even in the same environment; this can create disruption and continuity.

Another example is Diane, who does not always like to disclose the dementia diagnosis of her husband but in some situations feels the need to do so. When John made inappropriate signs to another driver and he and Diane ended up in an incident of road rage, Diane did not see another possibility than disclosing her husband’s dementia diagnosis to the other driver by referring to the stigma that people with dementia do not know what they are doing. When she disclosed this information, the other driver calmed down and even apologised to John and Diane and patted John

on the head. Disclosing this information also meant that Diane identified with being the carer of John and making sure he did not get hurt. Their identities shifted from husband and wife to carer and person with dementia in one situation. Shifting this identity created continuity again as it coped with the possible disruption of John and the other driver having a fight.

The social environment not only influences the identity verification process, but it can also challenge it. In the case of Hamid and Aaisha, their son does not acknowledge his mum's new role as decision maker in the marriage; neither do all the health care professionals and services they access. Adapting this new role is already a challenge for Aaisha as it challenges her habitus, the behaviour she associates with being a wife, and the failure of others to verify this new identity of hers makes it even more difficult to for her to identify with this new role and identity.

The identity perspective is a useful perspective for looking at dementia-friendly communities and current debates in dementia care that like to focus on the abilities of someone with dementia and his or her role in society like dementia and citizenship. We need to keep in mind that people with dementia often have well-established identities and roles in their community, for example, Sue who always used to go on the bus on her own or Hamid who used to be the leader of a community centre. These identities and roles do not suddenly disappear when someone develops dementia but they might become even more context- and situation-dependent; Sue for example is acknowledged as being able to go on the bus on her own until she behaves confused and she is identified as having dementia.

9.3 Reflection on Methods and Methodology

Because I already included a thorough reflection on the research design and process in Chapter 8 and reflected on my methods in Chapter 3, I will keep the reflection in this section brief and summarise my most important reflections. I will first reflect on the methods. Some methods had to be adjusted during the study: the life history interview and the photo diary method. The life history interview method I used was too structured to interview participants with dementia. After I tried to do two structured life history interviews I decided to take a more flexible approach and invite the participants with dementia to tell me the parts of the past that they could remember and liked to tell me about.

I also had to adjust the photo diary method. When I chose the method I wanted to ask all participants to keep an individual photo diary for 28 days in a row in order to create a better inside in their daily lives from both spouses perspectives over a month time. Even though I was aware of the fact that couples might tell each other about the pictures they would take, ask each other for help and/or provide each other with prompts I did assume that both individuals could keep their own diary. I provided all spouses with clear instructions/a protocol on how to conduct the photo diary study[30]. Nevertheless, only one couple kept two individual diaries; all other couples shared the diary, and this would usually mean that the caring spouse would take most pictures.

One of the reasons I included the photo diary study was to give participants the opportunity to participate actively in the research process, especially the spouses with dementia because interviewing was not always the best method to include them. That the participants used their agency to change the protocol on the one hand showed how they became actively involved as co-researcher and confirmed the participatory nature and goal of the method but on the other hand this goal was only partly accomplished. In some couples the spouse with dementia also took some pictures which offered them some opportunity to participate, but in other couples the caring spouses took all pictures. In one case the caring spouse took all the pictures because the person with dementia did not want to take pictures. In the other case the caring spouse told me that she did not consider her husband to be able to take pictures.

Although keeping the photo diaries did not offer the type of participatory involvement I expected for the spouses with dementia. This practice did give me a valuable insight into the dynamics between the spouses. It showed how decision-making dynamics between the couple and how the spouse carer did or did not try to keep the person with dementia actively involved in shared activities. Whereas keeping a photo diary did not facilitate participation of all participants, the photo voice interviews did offer this type of involvement. The pictures facilitated a conversation both between the spouses and with the researcher in which they reflected on daily life and provided topics for further informal interviews. In some instances, these photovoice interviews enabled the couples to connect over shared memories

[30] Please find these instructions in appendix 3.3

because the photos functioned as an aid for the memory of the spouses. While in other instances the confrontation with memories connected to the pictures confronted the spouses with the loss of shared activities and or abilities. This also provided me with insight into the dynamic within the couple and how they coped with the changes in their daily lives and relationship.

Another challenge with this method was the chronological aspect. I asked the couples to take one picture every day for 28 days in a row. Only one couple followed these instructions. All the other couples either took longer to take 28 pictures or did not even take 28 pictures and still took longer than a month. This meant that I could not ask them how these pictures represented that particular month. At first, I was interested in finding returning topics over the month and I was worried that these topics would not show if the camera was not used on a strict time line.

Eventually I decided to allow the participants as long as they needed to take the number of pictures they liked, as long as it was on their daily life experience and did not exceed the number of pictures in the disposable camera. It was more important to me that they could share with me the parts of their daily life they liked to share in the pictures, instead of the earlier aim of a chronological order of the pictures. When the pictures were developed this chronological order was further challenged because the disposable pictures did not print a date on the pictures.

On the one hand the lack of chronological order of the pictures, and the variety in the number of pictures participants took and the multiplicity of pictures of one event made it more difficult to compare the different photo-diaries while it on the other hand strengthen the participants agency to create a photo diary the way they envisaged it. Participants gained more freedom to focus on the events they liked to share with the researcher by only photographing those and sometimes including multiple picutres of the same event , for example Hamid and Aaisha included multiple pictures of Hamid's birthday party. The importance of this event was discussed in Chapter 6.

Even though the participatory value of this method was less than expected and the participants did not follow the protocol which meant I could not use the pictures to compare the different cases it still offered valuable data from the viewpoint of the participants for each individual case which matched well with the interpretivist approach of the study. Furthermore, the repeating themes that I was hoping to find in the chronological order pictures also appeared in the non-

chronologically organised photo diaries. Some of the challenges were caused by the use of a disposable camera; still, I do not regret using this device. It is easy to use, which was a major asset to my participants as some of them had never used a camera before.

Now that I have reflected on two specific methods which I have adjusted to the needs of the participants during the study I will give a short summary of some of the main reflections on my methodology: an interpretivist ethnography.
The main challenge of this study was to match desired approaches to the pragmatics a limited study time. I could only do six months of fieldwork, while classic ethnographic fieldwork takes up to a year. Just like in many other studies recruitment was a challenge because it was time consuming. I only had a month to recruit the participants which was challenging because the groups I visited to recruit often only took place once a month. In future research I would prefer to have a bit more time for the recruitment and fieldwork, and to be able to have multiple fieldwork sessions with time in between to do preliminary data analysis and reflection.

I also had to be aware of my own multiple identities while being in the field. I had to draw boundaries in order to keep the researcher–participant relationship. Some participants asked me for advice as if I was a health care professional, others offered me friendship and one couple offered to treat me as their daughter. Even though I sometimes liked to accept a friendship or give advice I refrained from this during the fieldwork and emphasised that I was a researcher.

Another challenge in the field were emotions, both the confrontation with emotions of the participants and my own emotions. Two emotional moments for both the participants and me were the moment when Alan had to go on a palliative care pathway and he and Jane withdrew from the study and when Dan told me that Mary had passed away not long after the fieldwork. In both cases I gave the participants the space to cope with their own emotions and stayed in touch in the background, either by sending them a card or by visiting for a cup of tea when invited. My personal diary and Skype sessions with a fellow anthropologist helped me to cope with these emotions.

Overall, the different methods of data collection – informal interviews, semi-structured interviews, life history interviews, participant observation, field notes and the photo diary method – worked well together. The informal interviews gave me the flexibility to talk to participants about topics while leaving a lot of space for them to

bring up topics and or stories that they found important in their daily life or past daily life. The semi-structured interviews were good as a back-up when the informal interviews did not cover all topics of my topic list.

The life history interviews contributed a lot to the holistic perspective of the study. A reflection on the most important past experiences in someone's life and their norms and values gave me valuable information on their habitus and sometimes created a better understanding of the coping strategies they used in their current daily life. In the case of Bob and Sue, Bob's life history interview showed clearly the importance of their marriage in his life and created a better understanding of his response to his wife's denial of the marriage. In the case of Hamid and Aaisha, Aaisha's life history created a better understanding of the role of religion in their life and the difficulty she experienced adopting to her new role as decision maker in the marriage.

The participant observation was valuable for multiple reasons; it gave me a better understanding of what their daily life was like and the type of challenges they would encounter. An example of this is when I joined on a bus ride, I noticed that Sue was wearing the wrong glasses and how this enhanced her confusion; otherwise I would possibly not have noticed how a simple thing like glasses would influence a situation like that. Another example is when I visited Bob and Sue, Sue was not there and Bob was waiting for a phone call from the police to let him know they found her. In that situation I could feel the stress and uncertainty in the room. Participant observation also enabled me to observe embodiment of the habitus, as when Hamid tried to teach me some verses from the Quran, embodying his former identity as a teacher. Furthermore, it enabled me to observe how others in the community influenced the changes in identity of the couples, as with Aaisha's telephone conversation with the GP practice or the visit of the police to their house, in which Aaisha did not feel heard.

Lastly, participant observation helped me to understand the interaction of the spouses with their environment. For example, I noticed how Sue misplaced her stockings under the cushions of the couch and how normal Sue and Bob seemed to think that was. And I noticed how Hamid could not find the bathroom in their own house without the directions of Aaisha.

The field notes gave me the opportunity to reflect on my participant observation and to write extensive notes on these events. The field notes gave me a

valuable document which created a foundation for most of the vignettes that have been included in this thesis. It also offered me a space to bring the participant observations together with reflections on the interview data and photo diary data.

As mentioned before the photo diary method study was valuable as it offered the participants an opportunity to include pictures of part of their daily life experience that they found important to show me, and the photo elicitation interviews offered them a space to reflect on these parts of their daily life which gave a truly interpretivist view in to their daily life experience. These photos also showed me activities of their daily life on which I had not joined them and thus gave me a better idea of their day-to-day activities and routine. Furthermore, the diary especially gave me a better insight in how they engaged with the community and their relationship with other family members. The photo diaries especially provided me with information on how participants interacted with their environment, their norms and values and their bodies.

Overall, the different methods created a holistic understanding through providing a better insight into the different concepts from the theoretical framework: body, environment, habitus and common sense, their interaction together and how they could give a better insight in the topics, relationship, daily routine, identities, dementia and co-morbidities. Not only did the different methods work well together to provide this holistic understanding, but they also worked as a triangulation method, increasing the validity of the data. Some data from the interviews was, for example, confirmed by the photo diary, while at other times the photos or the participant observation challenged interview data and made me ask more questions, which created a better understanding of this ambiguity.

I think these methods were the right methods to use for the project and I am pleased with the adjustments I made to the life history and photo diary method. Although the data collection methods worked well in this study, in future research I would like to spend more time on designing more participatory methods for people with dementia. As discussed earlier on, the photo diary method was not as participatory as I expected it to be. Lately more researchers in dementia care acknowledge the importance of including people with dementia as participants or even co-researchers. I find this an important development and would like to spend more time on developing methods that enable people with dementia to do so.

Besides the data collection method, I am also pleased with the framework analysis method in combination with the case study approach. The method offered me a structured approach to efficiently analyse a large amount of data and different documents like the case study framework and case study report in which I could easily report the data on each topic and find it again quickly during the data interpretation phase.

Although it offered a structured process there was still room for both inductive and deductive data analysis, which matched well with the explanatory research method I wanted to develop, including the collection of empirical data.

9.4 Strengths, Limitations and Future Research

Before I come to a conclusion, it is important to reflect on the strengths and limitations of this study. Strengths of this study were the holistic perspective that worked well in combination with the interpretative ethnography. I was able to present a thick description of the daily life experience of these spouses in a format in which it has not been presented before and drawing upon a wide range of qualitative methods. Another strength of the study was the inclusion of a focus on co-morbidities. An additional strength of this thesis is both the development of a new perspective drawing upon established theory and the collected empirical data that provides knowledge on the lived experience. A further strength is that this study presented a longitudinal research study which followed five couples over six months and included building up a high level of rapport. Additionally, this study has offered an explanatory research approach while most existing qualitative research is explorative, as shown in Chapter 2. And finally this study included a high level of reflexivity, which is unusual in research in this area as shown in Chapter 2.

Even though the holistic perspective is a strength of the study, I have not been able to research all aspects of the participants' daily life that may influence their experience in detail. In this thesis I did not give special attention to understanding how gender and ethnic background influence the daily life experience of the couples. I did collect some data on these topics but there was not enough time in the project to develop the approach to a level that included these aspects of the daily life experience.

Still, the approach I introduced in this thesis could be further developed by including a focus on other aspects of the daily life experience, such as gender and ethnic background. The usefulness of other concepts in Bourdieu's theory of practice including economic capital, social capital and cultural capital could be explored to gain a better understanding of how socio-economic position and cultural background influence the daily life experience of living with dementia. It would be interesting to use Bourdieu's theory of practice on the macro level of inter-group comparison, as his theory is most commonly used, in order to compare the individual experiences, the couples on group level according to their cultural background, socio-economic position and capital ownership.

If we would like to gain a better understanding of the influence of gender on this lived experience we may have to include an extra concept to the approach, as a well-known point of criticism on Bourdieu's theory of practice is the exclusion of gender as a concept that influences the behaviour. Nevertheless, suggestions have been made as to how gender can be included in his theory of practice (McNay 1999).

Another limitation of the study is its limited generalisability. The sample of this study was relatively small – only ten participants – and as explained in Chapter 2 the results of this study cannot be generalised to say something about the daily life experience of people with dementia and co-morbidities and their spouses in general. But the sample of five couples is big enough to say something about the usefulness of the theoretical framework, in this case an identity perspective, to understand the daily life of the couples better. In this thesis I have shown how this theoretical approach could create such an understanding focussing on the daily life routine, relationship of the couple and individual identities.

9.5 Implications for Policy and Practice

This thesis focussed on developing an explanatory research approach and perspective that created a better understanding, not on developing recommendations and/or interventions for care. Still, it is important to discuss the possible implications the knowledge on the lived experience presented in this thesis could have for policy and practice. One of the aims of this study is to provide knowledge to improve services for co-habiting spouses of whom one has got

dementia and co-morbidities and the partner is the primary carer.

As mentioned in the introduction the English government would like to provide person-tailored care and support to everyone living with dementia and their carers, friends and family. In order to provide this type of care and support they will have to understand the diverse needs of different people with dementia and their carers, friends and family members.

To provide care and support that acknowledges this diversity in needs and preferences, it will be helpful to adapt a holistic and dynamic perspective to look at the daily life experience with dementia of each individual. With a holistic approach in care and service I mean using a perspective to look at the needs of the couple that takes into account many aspects of life and seeks to explore the connections between them and their influence on care and service needs instead of a cause and effect approach which identifies a need and a service without taking into consideration their connection to and implication for many other aspects of life. Dynamic approach means using a perspective that takes into consideration the changes within the daily life of the couple over time and which is flexible so the service can change when the needs of the couple change.

In the literature review in Chapter 2 it already became clear that in existing literature there is a need for this type of perspective and personally tailored care and support. Most of the articles explain well which elements of diversity healthcare providers, social care providers, health workers and professional carers should take into account but fail to provide specific guidance on how this could best be accomplished.

This thesis is also unable to provide specific guidance on how this could best be accomplished. Nevertheless, it offers a perspective based on an identity approach that creates a holistic and dynamic understanding of the lived experience of spouses of whom one has dementia (and co-morbidities) and the partner is the carer. This perspective could be adopted in practice to gain a better understanding of the lived experience of these spouses, which could help professionals to tailor care and support to the specific needs and preferences of the couples and individuals. The next step would be to develop and test care interventions that are based on this perspective to be able to provide specific care and support on specific challenges in their daily lives.

Also, this thesis shows the importance of looking at how both dementia and co-morbidities could create challenges in daily life and how dementia and co-morbidities could make it difficult to cope with these challenges, as clearly illustrated in the example of Mary who has a stairlift to be able to climb the stairs despite her mobility problems but whose dementia makes it difficult to know how to use the stairlift. Healthcare and service providers should also take into consideration that this difficulty coping can create a more complex care situation for the caring spouse and a more intensive care situation. In this example it means that Dan always needs accompany Mary when she wants to go up or down the stairs.

Furthermore, this thesis shows that we need to reconsider the dominant ideas about the importance of ageing in place for people with dementia in policy and practice. Which environment is familiar and reduces confusion varies even within short amounts of time. Sometimes the home environment where a couple has lived for over forty years still becomes unfamiliar and creates confusion and challenges in the daily life and the relationship of the couple. Therefore, as mentioned before in the discussion, policy should pay more attention to the possibility that aging in place is not always the best scenario for people with dementia and their spouses. Policy should provide and explore more alternatives to aging in place.

In summary the identity perspective presented in this thesis could be translated in both care practice and policy through looking at the care recipients as people who hold multiple identities in their daily lives. Those identities will create different needs. When policy makers and care providers are aware of this variety of needs connected to identities, they can provide person-tailored care that enables people with dementia and their spouses to continue their daily-life routines and sustain certain roles and identities in the community longer.

Furthermore, the tailored support could help them to adapt to changes in these roles and routines more easily. An example of these diverse needs can be found in the vignettes presented in this thesis, sometimes someone with dementia is the recipient of help and support because of their dementia and co-morbidities while in other situations they are the supportive neighbour, Alan, or the independent traveller, like Sue when she takes the bus on her own. In the situations when they are the supportive neighbour or independent traveller, they will need a different type of support. Sue for example was offered a GPS tracker to enable her to keep travelling alone while her husband knows where she is if she gets lost.

9.6 Conclusion

This thesis both confirms some of the existing knowledge on spouse care of people with dementia and co-morbidities who live together in the community in England and challenges it. Most of all, the rich data presented in the thesis in combination with the developed identity perspective showed how the identified challenges and processes in the existing knowledge are context dependable and situational over even small amounts of time. Furthermore, this thesis provides a more in-depth understanding of the relationship redefinition process which challenges the current views of phases that follow each other as discussed in Chapter 6. Instead it shows how it is an ongoing process which differs over time and environment and depends on the influence of the dementia and the co-morbidities in that particular moment: Is the habitus inaccessible? Is the body able to embody the habitus? Does this create a confirmation or rejection of the relationship and its associated identities? Not only do dementia and its cognitive impairment complicate this redefinition process, but co-morbidities further challenge it, adding to the difficulty by creating a loss of more abilities, contributing to both the challenge of co-morbidity and the complexity of the verification process as more roles and tasks need to be taken over by the caring spouse.

Also, the thesis showed how dominant ideas about dementia like the stigma influence the process of relationship redefinition, creating both disruption and continuity in the spouses' daily life. Whether spouses identify with the stigma also depends on the social situation. This identification with or rejection of the stigma influences the acceptance or rejection of the dementia diagnosis in different situations, which influences the access to care, support and knowledge.

Not only the dominant ideas of dementia in society but also the assumptions of individuals in the community and friends and family influence the identity verification process of people with dementia and their spouses in different situations. This can influence both their relationship redefinition process and their engagement in the community and family.

To conclude, the daily life experience of people with dementia and their spouses and the disruptions they experience are changeable over time and context dependable. Spouses will try to create continuity to cope with these disruptions in

which they rely on their habitus and identities, both individual and shared identities. Their identities, both individual and shared, can be both challenged and confirmed by the dementia, co-morbidities, stigma and expectations and ideas of the people they interact with – friends, family and community members. Most importantly this thesis shows how we need to adopt a perspective to look at the daily life experience that is holistic and dynamic, illuminating the fluidity, complexity, and contextuality of the daily life experiences and its challenges for spouses living with dementia and co-morbidities in the community.

References

Adler, P. A. and Adler, P. (1987) *Membership roles in field research.* Vol. 6. London: Sage.

Alzheimer's Society (2014) *Dementia 2014 report statistics.* Alzheimer's Society. Accessed 23/05/2015. https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report.

Alzheimer's Society (2017) *Activity groups.* https://www.alzheimers.org.uk/info/20172/your_support_services/1082/activity_groups: Alzheimer's Society. Accessed 03/04/2018.

Alzheimer's Society (2018) *Dementia-friendly communities.* www.alzheimers.org.uk/get-involved/dementia-friendly-communities: Alzheimer's Society. Accessed 07/06/2018.

Angus, J., Kontos, P., Dyck, I., McKeever, P. and Poland, B. (2005) The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of health & illness* 27(2), 161–187.

APPG, A. P. P. G. o. D. (2016) *Dementia rarely travels alone: living with dementia and other conditions.* Parliament. London: APPG.

Atkinson, W. (2016) *Beyond Bourdieu, from genetic structuralism to relational phenomenology.* Cambridge: Polity Press.

Baarda, D., De Goede, M. and Teunissen, J. (2009) *Basisboek kwalitatief onderzoek: handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek.* Stenfert Kroese Groningen.

Baldwin, C. and Capstick, A. (2007) *Tom Kitwood on dementia: a reader and critical commentary.* New York: McGraw Hill Open University Press.

Ballanger, J. F. (2006) The biomedical deconstruction of senility and the persistent stigmatization of old age in the United States. In Leibing, A. and Cohen, L. (editors) *Thinking about dementia: culture, loss, and the anthropology of senility.* London: Rutger University Press, 106-122.

Barrett, S. R. (2009) *Anthropology: a student's guide to theory and method.* 2nd edition. London: University of Toronto Press.

Bartlett, R. (2012) Modifying the diary interview method to research the lives of people with dementia. *Qualitative health research* 22(12), 1717–1726.

Bartlett, R. (2014a) Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society* 29(8), 1291–1304.

Bartlett, R. (2014b) The emergent modes of dementia activism. *Ageing and Society* 34(04), 623–644.

Bartlett, R. (2016) Scanning the conceptual horizons of citizenship. *Dementia* 15(3), 453–461.

Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of aging studies* 21(2), 107–118.

Bartlett, R. and O'Connor, D. (2010) *Broadening the dementia debate: Towards social citizenship.* Policy press.

Bauer, K., Schwarzkopf, L., Graessel, E. and Holle, R. (2014) A claims data-based comparison of comorbidity in individuals with and without dementia. *BMC Geriatrics* 14(1), 10.

Beard, R. L. (2016) *Living with Alzheimer's: managing memory loss, identity and illness.* New York: New York University Press.

Beard, R. L., Sakhtah, S., Imse, V. and Galvin, J. E. (2012) Negotiating the joint career: couples adapting to Alzheimer's and aging in place. *Journal of Aging Research* 2012, 797023, 1-12.

Becker, G. (1997) *Disrupted lives: How people create meaning in a chaotic world.* Berkley: University of California Press.

Bergman, M., Graff, C., Eriksdotter, M., Fugl-Meyer, K., Schuster, M. and Fugl-Meyer, K. S. (2016) The meaning of living close to a person with Alzheimer disease. *Medicine, Health Care & Philosophy* 19(3), 341–349.

Birt, L., Poland, F., Csipke, E. and Charlesworth, G. (2017) Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness* 39(2), 199–211.

Boeije, H. (2010) *Analysis in qualitative research.* London: Sage.

Boeije, H., t' Hart, H. and Hox, J. (2009) *Onderzoeksmethoden.* 8th edition. Amsterdam: Boomonderwijs.

Bosch, R. (2012) *Wetenschapsfilosofie voor kwalitatief onderzoek.* Den Haag: Boom Lemma.

Botsford, J., Clarke, C. L. and Gibb, C. E. (2012) Dementia and relationships: experiences of partners in minority ethnic communities. *Journal of Advanced Nursing* 68(10), 2207–2217.

Bourdieu, P. (1977) *Outline of a theory of practice.* Vol. 16. Cambridge: Cambridge University Press.

Bourdieu, P. (1984) *Distinction: a social critique of the judgement of taste.* London: Routledge & Kegan Paul.

Bourdieu, P. (1990) *The logic of practice.* Cambridge: Polity Press.

Bourdieu, P. (1998) *Practical reason: on the theory of action.* Oxford: Polity.

Bourdieu, P. (2000) *Pascalian meditations.* Standford: Stanford University Press.

Bourdieu, P. (2000) *The Weight of the World: Social Suffering in Contemporary.* Standford: Stanford University Press.

Bourdieu, P. and Wacquant, L., J. D. (1992a) The Purpose of Reflexive Sociology (The Chicago Workshop). In Bourdieu, P. and Wacquant, L. J. D. (editors) *An Invitation to Reflexive Sociology.* Cambridge: Polity Press, 61-202.

Bourdieu, P. and Wacquant, L. c. J. D. (1992b) *An invitation to reflexive sociology.* Cambridge: Polity Press.

Boyle, G. (2010) Social policy for people with dementia in England: promoting human rights? *Health & social care in the community* 18(5), 511–519.

Boyle, G. (2013) 'She's usually quicker than the calculator': financial management and decision-making in couples living with dementia. *Health & Social Care in the Community* 21(5), 554–562.

Boyle, G. (2014) 'Can't cook, won't cook': men's involvement in cooking when their wives develop dementia. *Journal of Gender Studies* 23(4), 336–350.

Brown, J. W., Chen, S.-l., Mitchell, C. and Province, A. (2007) Help-seeking by older husbands caring for wives with dementia. *Journal of Advanced Nursing* 59(4), 352–360.

Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J. and Brayne, C. (2014) Comorbidity and dementia: a scoping review of the literature. *BMC Medicine* 12(1), 192.

Bunn, F., Burn, A.-M., Robinson, L., Poole, M., Rait, G., Brayne, C., Schoeman, J., Norton, S. and Goodman, C. (2017) Healthcare organisation and delivery for

people with dementia and comorbidity: a qualitative study exploring the views of patients, carers and professionals. *BMJ open* 7(1), e013067.

Bunn, F., Goodman, C. and Burn, A.-M. (2015) Multimorbidity and frailty in people with dementia. *Nursing Standard* 30(1), 45–50.

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E. and Iliffe, S. (2012) Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Medicine* 9 (10), e1001331.

Burke, P. J. and Stets, J. E. (2009) *Identity theory.* Oxford: Oxford University Press.

Butcher, H. K., Holkup, P. A. and Buckwalter, K. C. (2001) The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research* 23(1), 33–55.

Buytendijk, F. J. J. (1965) *Prolegomena van een antropologische fysiologie.* Utrecht: Spectrum.

Caddell, L. S. and Clare, L. (2010) The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review* 30(1), 113–126.

Capstick, A. (2012) Participatory video and situated ethics avoiding disablism. In Milne, E.-J., Mitchell, C., and Delange, N. (editors) *Handbook of participatory video.* Plymouth: Altamira Press.

CASPUK (2018) *CASP Checklists.* https://casp-uk.net/casp-tools-checklists/: CASPUK. Accessed 24/07/2018.

Cassell, J. (2016) *Case 21: Ethical dilemmas and moral responsibilities*. www.americananthro.org, American Anthropology Association. Accessed on 27/06/2016.

Chaplin, E. (2004) My visual diary. In Knowles, C. and Sweetman, P. (editors) *Picturing the social landscape: visual methods and the sociological imagination.* London: Routledge, 35-48.

Chaudhury, H. and Rowles, G. D. (2005) Between the Shores of Recollection and Imagination: Self, Aging and Home. In Rowles, G. D. and Chaudhury, H. (editors) *Home and Identity in Late Life: International Perspectives.* New York: Springer Publishing Company, 3-18.

Chung, P. Y. F., Ellis-Hill, C. and Coleman, P. G. (2008) Carers' perspectives on the activity patterns of people with dementia. *Dementia* 7(3), 359–381.

Clare, L. (2002) We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging & mental health* 6(2), 139–148.

Close, H. (2007) The use of photography as a qualitative research tool. *Nurse Researcher* 15(1), 27.

Cohen, L. (1998) *No aging in India: Alzheimer's, the bad family, and other modern things.* Berkley: University of California Press.

Cohen, L. (2006) Introduction: thinking about dementia. In Leibing, A. and Cohen, L. (editors) *Thinking about dementia: culture, loss and the anthropology of senility.* London: Rutger University Press, 1-19.

Connell, C. M., Janevic, M. R. and Gallant, M. P. (2001) The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4), 179–187.

Crapanzano, V. (2010) "At the heart of the discipline" critical reflections on fieldwork. In Davies, J. and Spencer, D. (editors) *Emotions in the Field.* Stanford: Stanford University Press, 55-79.

Crooks, V. C., Lubben, J., Petitti, D. B., Little, D. and Chiu, V. (2008) Social network, cognitive function, and dementia incidence among elderly women. *American Journal of Public Health* 98(7), 1221–1227.

Daniels, K. J., Lamson, A. L. and Hodgson, J. (2007) An exploration of the martial relationship and Alzheimer's disease: one couple's story. *Families, systems & health: The Journal of Collaborative Family Healthcare* 25(2), 162–177.

Davey, M. (2015) Alzheimer's and dementia are second biggest Killer in Australia, data shows.The Guardian UK, 20/10/2015.

Davies, J. and Spencer, D. (2010) *Emotions in the field: the psychology and anthropology of fieldwork experience.* Standford: Stanford University Press.

de Vugt, M. and Dröes, R.-M. (2017) Social health in dementia. Towards a positive dementia discourse. *Aging and Mental Health,* 21(1) 4-17.

Deep (2015) *Deep: The Dementia Engagement and Empowerment Project.* http://dementiavoices.org.uk/ Accessed 27/06/2016.

DeWalt, K. M. and DeWalt, B. R. (2010) *Participant observation: a guide for fieldworkers.* New York: Rowman Altamira.

Dewing, J. (2007) Participatory research: a method for process consent with persons who have dementia. *Dementia* 6(1), 11–25.

Dixon, J., Laing, J. and Valentine, C. (2018) A human rights approach to advocacy for people with dementia: a review of current provision in England and Wales. *Dementia*, 0(0) 1–16

DoH, D. o. H. (2015) *Prime Ministers' Challenge on Dementia 2020.* London: Department of Health.

Doraiswamy, P. M., Leon, J., Cummings, J. L., Marin, D. and Neumann, P. J. (2002) Prevalence and impact of medical comorbidity in Alzheimer's disease. *The journals of gerontology series A: biological sciences and medical sciences* 57(3), M173–M177.

Downs, M. (2013) Embodiment: the implications for living well with dementia. *Dementia* 12(3), 368–374.

Dröes, R., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., Verbeek, H., Vernooij-Dassen, M., Clare, L. and Johannessen, A. (2017) Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging & Mental Health* 21(1), 4–17.

Eriksson, H., Sandberg, J. and Hellström, I. (2013) Experiences of long-term home care as an informal caregiver to a spouse: gendered meanings in everyday life for female carers. *International Journal of Older People Nursing* 8(2), 159–165.

Erol, R., Brooker, D. and Elizabeth, P. (2015) *Women and Dementia: a global research review.* London: Alzheimer Disease International.

Farrugia, D. and Woodman, D. (2015) Ultimate concerns in late modernity: Archer, Bourdieu and reflexivity. *The British Journal of Sociology* 66(4), 626–644.

Fay, B. (1996) *Contemporary philosophy of social science: a multicultural approach.* Oxford: Blackwell.

Feil, D. G., Zhu, C. W. and Sultzer, D. L. (2012) The relationship between cognitive impairment and diabetes self-management in a population-based community sample of older adults with Type 2 diabetes. *Journal of Behavioral Medicine* 35(2), 190–199.

Fife, W. (2005) *Doing fieldwork: ethnographic methods for research in developing countries and beyond.* London: Pallgrave Macmillan.

Fontein, J. (2014) Doing research fieldwork practicalities. In Konopinski, N. (editor) *Doing anthropological research: a practical guide.* London: Routledge. 70–89.

Fratiglioni, L., Wang, H.-X., Ericsson, K., Maytan, M. and Winblad, B. (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. *The Lancet* 355(9212), 1315–1319.

Fuchs, E. (2005) *Making an exit: a mother-daughter drama with Alzheimer's, machine tools, and laughter.* New York: Macmillan.

Fusch, P. I. and Ness, L. R. (2015) Are we there yet? Data saturation in qualitative research. *The Qualitative Report* 20(9), 1408.

Garro, L. (1992) Chronic Illness and the Construction of Narratives. In M.J. and Delvecchio Good, P. B., B. Good, and A. Kleinman (editors) *Pain as human experience: an anthropological perspective.* Berkeley and Los Angeles: University of California Press. 100–137.

Garro, L. C. (2011a) Enacting ethos, enacting health: Realizing health in the everyday life of a California family of Mexican descent. *Ethos* 39(3), 300–330.

Garro, L. C. (2011b) Trouble as part of everyday life: cognitive and sociocultural processes in avoiding and responding to illness. In Kronenfeld D. B.,de Munck, G. B. V. and Fischer, M.D. *A companion to cognitive anthropology*, 531–547.

Garro, L. C. and Yarris, K. E. (2009) “A massive long way”: interconnecting histories, a “special child,” ADHD, and everyday family life. *Culture, Medicine, and Psychiatry* 33(4), 559.

Geertz, C. (1973) *The interpretation of culture: selected essays.* New York: Basic Books.

Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowska, A. and Selmes, M. (2008) Alzheimer's disease in real life-the dementia carer's survey. *International Journal of Geriatric Psychiatry* 23(5), 546–551.

Gilgun, J. F. (2014) *Chicago school traditions: deductive qualitative analysis and grounded theory (2 Vols).* CreateSpace Independent Publishing Platform.

Gilleard, C. J. and Higgs, P. (2000) *Cultures of ageing: self, citizen, and the body.* Harlow: Prentice Hall.

Goffman, E. (1963) *Stigma: notes on the management of spoiled identity.* London: Penguin Books.

Goodall, P. (1990) Design and gender: where is the heart of the home? *Built Environment*, 16(4) 269–278.

Gove, D., Small, N., Downs, M. and Vernooij-Dassen, M. (2017) General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia* 16(7), 948–964.

Guerra, S. R., Rodrigues, S. P., Demain, S., Figueiredo, D. M. and Sousa, L. X. (2013) Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance. *Dementia* 12(5), 569–587.

Hak, T. (2007) Theorie toetsen in kwalitatief onderzoek. *KWALON. Tijdschrift voor Kwalitatief Onderzoek in Nederland* 36(3), 5–13.

Hammersley, M. and Atkinson, P. (2007) *Ethnography: principles in practice.* Vol. 3rd. London: Routledge.

Harman, G. and Clare, L. (2006) Illness representations and lived experience in early-stage dementia. *Qualitative Health Research* 16(4), 484–502.

Harrington, B. (2003) The social psychology of access in ethnographic research. *Journal of Contemporary Ethnography* 32(5), 592–625.

Heath, S. and Cleaver, E. (2004) Mapping the Spatial in Shared Household Life: A Missed Opportunity. In Knowles, C. and Sweetman, P. (editors) *Picturing the social landscape: visual methods and the sociological imagination.* London: Routledge, 65-79.

Heidegger, M. (1926) *Sein und Zeit.* 7 edition. Tubingen: Max Niemeyer Verlag.

Hellström, I., Nolan, M. and Lundh, U. (2007) Sustaining couplehood: spouses' strategies for living positively with dementia. *Dementia* 6(3), 383–409.

Holliday, R. (2004) Reflecting the self. In Knowles, C. and Sweetman, P. (editors) *Picturing the social landscape: visual methods and the sociological imagination.* London: Routledge, 49-65.

Hope, J. (2014) Dementia is now the leading killer of women, causing three times as many deaths as breast cancer. Daily Mail, 29/10/2014.

Hughes, J. C. (2013) 'Y'feel me?'How do we understand the person with dementia? *Dementia* 12(3), 348–358.

Hughes, J. C., Louw, S. J. and Sabat, S. R. (2006) Seeing whole. In Hughes, J. C., Louw, S. J., and Sabat, S. R. (editors) *dementia: mind meaning and the person.* Oxford: Oxford University Press, 1-41.

Jansson, W., Nordberg, G. and Grafström, M. (2001) Patterns of elderly spousal caregiving in dementia care: an observational study. *Journal of advanced nursing* 34(6), 804–812.

JSNA (2015) *Bradford joint strategic needs assessment: 6.1.2 Wellbeing amongst older people in Bradford's communities.* Bradford: Bradford Council.

Kaufman, S. R. (1994) *The healer's tale: transforming medicine and culture.* Wisconsin: University of Wisconsin Press.

Kaufman, S. R. (2006) Dementia-Near-Death and "life itself". In Cohen, L. and Leibing, A. (editors) *Thinking about dementia: culture, loss and the anthropology of senility.* London: Rutgers University Press, 23-42.

Kitwood, T. and Bredin, K. (1992) *Person to person: a guide to the care of those with failing mental powers.* Second edition. Essex: Gale Centre Publications.

Kontos, P. C. (2006) Embodied selfhood: an ethnographic exploration of Alzheimer's disease. In Leibing, A. and Cohen, L. (editors) *Thinking about dementia: culture, loss and the anthropology of senility.* London: Rutgers University Press, 125-218.

Kontos, P. C. and Martin, W. (2013) Embodiment and dementia: exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*, 12(3) 288–302.

Kontos, P. C. (2004) Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society* 24(06), 829–849.

Kontos, P. C. (2005) Embodied selfhood in Alzheimer's disease: rethinking person-centred care. *Dementia* 4(4), 553–570.

Kontos, P. C. (2011) Rethinking sociability in long-term care: an embodied dimension of selfhood. *Dementia*, 1–18.

Kotai-Ewers, T. (2011) Story matters in dementia care. In Lee, H. and Adams, T. (editors) *Creative approaches in dementia care.* Hampshire: Palgrave Macmillan. 160–173.

Kuiper, J. S., Zuidersma, M., Voshaar, R. C. O., Zuidema, S. U., van den Heuvel, E. R., Stolk, R. P. and Smidt, N. (2015) Social relationships and risk of dementia: a systematic review and meta-analysis of longitudinal cohort studies. *Ageing Research Reviews* 22, 39–57.

LeCompte, M. D. and Schensul, J. J. (1999) *Analyzing & interpreting ethnographic data.* Ethnographer's toolkit. Walnut Creek: Altamira Press.

Lesser, H. A. (2006) Dementia and personal identity. In Hughes, J. C., Louw, S. J., and Sabat, S. R. (editors) *dementia: mind, meaning and the person.* Oxford: University of Oxford Press.

Lock, M. (1993) Cultivating the body: anthropology and epistemologies of bodily practice and knowledge. *Annual Review of Anthropology* 22(1), 133–155.

Lock, M. (2013) *The Alzheimer conundrum*. Princeton, Princeton University Press.

Lock, M. and Farquhar, J. (2007) Introduction. In Lock, M. and Farquhar, J. (editors) *Beyond the body proper: reading the anthropology of material life.* Durham: Duke University Press, 1-18.

MacQuarrie, C. R. (2005) Experiences in early stage Alzheimer's disease: understanding the paradox of acceptance and denial. *Aging & Mental Health* 9(5), 430–441.

Martín-García, S., Rodríguez-Blázquez, C., Martínez-López, I., Martínez-Martín, P. and Forjaz, M. J. (2013) Comorbidity, health status, and quality of life in institutionalized older people with and without dementia. *International Psychogeriatrics* 25(07), 1077–1084.

Mauss, M. (1935) Techniques of the body. In Lock, M. and Farquhar, J. (editors) *Beyond the body proper: reading the anthropology of material life.* Durham: Duke University Press, 50-69.

McIntyre, A. (2003) Through the eyes of women: photovoice and participatory research as tools for reimagining place. *Gender, place & culture* 10(1), 47–66.

McKeown, J., Clarke, A., Ingleton, C. and Repper, J. (2010) Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing* 19 (13–14), 1935–1943.

McKillop, J. and Wilkinson, H. (2004) Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia* 3(2), 117–125.

McNay, L. (1999) Gender, habitus and the field: Pierre Bourdieu and the limits of reflexivity. *Theory, Culture & Society* 16(1), 95–117.

Merleau-Ponty, M. (1962) The phenomenology of perception. In Lock, M. and Farquhar, J. (editors) *Beyond the body proper: reading the anthropology of material life (2007).* Durham: Duke University Press, 133-150.

Milne, A. (2010) The ‘D’word: Reflections on the relationship between stigma, discrimination and dementia.*Journal of Mental Health19(3)* 227-233.

Mitchell, W. (2018) *Home*. https://whichmeamitoday.wordpress.com/, Wordpress. Accessed 10/05/2018.

Mol, A. (2006) *De logica van het zorgen: Actieve patienten en de grenzen van het kiezen.* Amsterdam: vanGennep.

Morhardt, D. and Spira, M. (2013) From person-centered care to relational-centered care. *Generations* 37(3), 37–44.

Mountain, G. A. (2016) Self-management programme for people with dementia and their spouses demonstrates some benefits, but the model has limitations. *Evidence-Based Nursing* 20(1): 26-27.

Mountain, G. A. and Craig, C. L. (2012) What should be in a self-management programme for people with early dementia? *Aging & Mental Health* 16(5), 576–583.

Murphy, K., Jordan, F., Hunter, A., Cooney, A. and Casey, D. (2014) Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia* 14(6), 800 - 824.

Murray, J., Schneider, J., Banerjee, S. and Mann, A. (1999) EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: II A qualitative analysis of the experience of caregiving. *International Journal of Geriatric Psychiatry* 14(8), 662–667.

Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M. and Glendinning, C. (2013) *A road less rocky: supporting carers of people with dementia.* London: Carers Trust.

NHS (2015) *Home environment and Dementia.* https://www.nhs.uk/conditions/dementia/home-environment/: NHS. Accessed 07/04/2018.

NHS and Trust, L. a. Y. P. F. (2018) *Memory Service, Younger People with Dementia and Memory Support Worker Teams.* https://www.leedsandyorkpft.nhs.uk/our-services/services-list/memory-services/: NHS. Accessed 03/04/18.

Nolan, M., Ryan, T., Enderby, P. and Reid, D. (2002) Towards a more inclusive vision of dementia care practice and research. *Dementia* 1(2), 193–211.

O'Shaughnessy, M. O., Lee, K. and Lintern, T. (2010) Changes in the couple 9(2), 237–258.

Oppenheimer, C. (2006) I am, thou art:personal identity in dementia. In Hughes, J. C., Louw, S. J., and Sabat, S. R. (editors) *dementia: mind, meaning, and the person.* Oxford: Oxford University Press, 193-204.

Parker, G. (1992) *With this body: caring and disability in marriage.* Buckingham: Open University Press.

Paun, O. (2003) Older women caring for spouses with Alzheimer's disease at home: making sense of the situation. *Health Care for Women International* 24(4), 292–312.

Perry-Young, L., Owen, G., Kelly, S. and Owens, C. (2018) How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography. *Dementia* 17(1), 34–60.

Pitts, M. J. and Miller-Day, M. (2007) Upward turning points and positive rapport-development across time in researcher—participant relationships. *Qualitative Research* 7(2), 177–201.

Plochg, T. and Van Zwieten, M. (2007) Kwalitatief onderzoek. *Handboek gezondheidszorgonderzoek.* Houten, Bohn Stafleu van Loghum. 77–93.

Preston, L., Marshall, A. and Bucks, R. S. (2007) Investigating the ways that older people cope with dementia: a qualitative study. *Aging & Mental Health* 11(2), 131–143.

Prince, M. J. (2015) World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International.*

Rabinow, P. (1977) Reflections on fieldwork in Morocco.Berkeley, University of California Press.

Radden, J. and Fordye, J. M. (2006) Into the darkness: losing identity with dementia. In Hughes, J. C., Louw, S. J., and Sabat, S. R. (editors) *dementia: mind, meaning and the person.* Oxford: Oxford University press, 71-88.

Ridley-Ellis, W. (2011) *Great places to grow old; Bradford District's housing strategy for the Over 50s 2011–2021.* Bradford: Bradford Council.

Ritchie, J. and Spencer, L. (2002) Qualitative data analysis for applied policy research. In Huberman, A. M. and Miles, M. B. (editors) *The Qualitative Researcher's Companion*. Sage Publications London, 305–329.

Sabat, S. R. (2001) *The experience of Alzheimer's disease: life through a tangled veil.* Blackwell Oxford.

Sabin, L. (2014) Dementia is 'the biggest killer for women'. The Independent, 29/10/2014.

Samsi, K. and Manthorpe, J. (2013) Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics / IPA* 25(6), 949–961.

Saunders, P. and Williams, P. (1988) The constitution of the home: towards a research agenda. *Housing Studies* 3(2), 81–93.

Scheper-Hughes, N. and Lock, M. M. (1987) The mindful body: a prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly* 1(1), 6–41.

Schweitzer, P. (2011) Innovative approaches to reminiscence: remembering yesterday, caring today. In Lee, H. and Adams, T. (editors) *Creative approaches in dementia care.* Hampshire: Palgrave Macmillan. 175–193.

Scrutton, J. and Urzi Brancati, C. (2016) *Dementia and comorbidities: ensuring parity of care*. London: The International Longevity Centre_UK (ILC-UK).

Shell, L. (2014) Photo-elicitation with autodriving in research with individuals with mild to moderate Alzheimer's disease: advantages and challenges. *International Journal of Qualitative methods* 13(1), 170–184.

Sherratt, C., Soteriou, T. and Evans, S. (2007) Ethical issues in social research involving people with dementia. *Dementia* 6(4), 463–479.

Shim, B., Barroso, J., Gilliss, C. L. and Davis, L. L. (2013) Finding meaning in caring for a spouse with dementia. *Applied Nursing Research: ANR* 26(3), 121–126.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R. S., Auret, K. A., Clayton, J. M., Agar, M. and Kurrle, S. (2018) How couples with dementia experience healthcare, lifestyle, and everyday decision-making. International Psychogeriatrics, 1-9.

Sixsmith, A. and Sixsmith, J. (2008) Ageing in place in the United Kingdom. *Ageing International* 32(3), 219–235.

Small, N., Froggatt, K. and Downs, M. (2007) *Living and dying with dementia: dialogues about palliative care.* Oxford: Oxford University Press.

Smith, A. P. (2006) Negotiating the moral status of trouble: the experiences of forgetful individuals diagnosed with no dementia. In Leibing, A. and Cohen, L. (editors) *Thinking about dementia: culture, loss, and the anthropology of senility.* London: Rutger University Press, 64-80.

Snowden, M. (2015) Use of diaries in research. *Nursing Standard (Royal College of Nursing (Great Britain) : 1987)* 29(44), 36–41.

Stodulka, T. (2015) Emotion work, ethnography, and survival strategies on the streets of Yogyakarta. *Medical Anthropology* 34(1), 84–97.

Swarbrick, C. M., Doors, O., Group, S. D. W., EDUCATE, Davis, K. and Keady, J. (2016) Visioning change: co-producing a model of involvement and engagement in research (Innovative Practice). *Dementia* 0(0), 1–8.

Synnott, A. (2003) *The body social: symbolism, self and society.* London: Routledge.

Tanner, D. (2012) Co-research with older people with dementia: experience and reflections. *Journal of Mental Health* 21(3), 296–306.

TeamDementia (2012) *Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015*. Leeds, Department of Health; Older People and Team Dementia.

Thane, P. (2000) *Old age in English history: past experiences, present issues.* Oxford: Oxford University Press.

Turner, B. S. (1996) *The body and society: explorations in social theory.* Second edition. London: Sage Publications.

Twigg, J. (2000) *Bathing, the body and community care.* Vol. 1. London: Routledge.

Twigg, J. (2006) *The body in health and social care.* London: Palgrave Macmillan.

UniversityofBradford (2018) *Experts by Experience.* https://www.brad.ac.uk/health/dementia/experts-by-experience/: University of Bradford. Accessed 14/07/2018.

van der Geest, S. (2017) The freedom of anthropological fieldwork. *Etnofoor* 29(1), 101–112.

Vandebroeck, D. (2017) *Distinctions in the flesh, social class and the embodiment of inequality.* London: Routledge.

Velzke, K. and Baumann, S. L. (2017) Including the voice of older adults in research. *Nursing science quarterly* 30(1), 67–72.

Vikström, S., Borell, L., Stigsdotter-Neely, A. and Josephsson, S. (2005) Caregivers' self-initiated support toward their partners with dementia when performing an everyday occupation together at home. *OTJR: Occupation, Participation & Health* 25(4), 149–159.

Vikström, S., Josephsson, S., Stigsdotter-Neely, A. and Nygård, L. (2008) Engagement in activities: experiences of persons with dementia and their caregiving spouses. *Dementia* 7(2), 251–270.

Volpe, J. (2018) *Making later life better in Leeds.* https://www.ageing-better.org.uk/news/making-later-life-better-leeds: Centre for Aging Better. Accessed 02/05/2018.

Wacquant, L. J. D. (1992) Toward a social praxeology: the structure and logic of Bourdieu's sociology. In Bourdieu, P. and Wacquant, L. J. D. (editors) *An invitation to reflexive sociology.* Cambridge: Polity Press, 1-60.

Walters, A. H., Oyebode, J. R. and Riley, G. A. (2010) The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia* 9(2), 169–189.

Warburton, N. (2011) The prince and the cobbler: John Locke and Thomas Reid. In Warburton, N. (editor) *A little history of philosophy.* London: Yale University Press, 81-87.

Ward, D. J., Furber, C., Tierney, S. and Swallow, V. (2013) Using framework analysis in nursing research: a worked example. *Journal of Advanced Nursing* 69(11), 2423–2431.

Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K. and Keady, J. (2017) The lived neighborhood: understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, 1–14.

Werner, P., Mittelman, M. S., Goldstein, D. and Heinik, J. (2011) Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist* 52(1), 89–97.

Whincup, T. (2004) Imaging the intangible. In Knowles, C. and Sweetman, P. (editors) *Picturing the social landscape: visual methods and the sociological imagination.* London: Routledge.

WHO, W. H. O. (2015) *ENSURING A HUMAN RIGHTS-BASED APPROACH FOR PEOPLE LIVING WITH DEMENTIA*. WHO website (http://www.who.int/mental_health/neurology/dementia/en/), World Health Organization. Accessed 02/05/2018.

WHO, W. H. O. (2012) *Dementia: a public health priority.* World Health Organization.

Wiersma, E. C. and Denton, A. (2016) From social network to safety net: Dementia-friendly communities in rural northern Ontario. *Dementia (London, England)* 15(1), 51–68.

Yin, R. K. (2003) *Case study research: Design and Methods.* third edition. London: Sage.

Yin, R. K. (2013) *Case study research: Design and Methods.* fifth edition London: Sage.

Zarit, S. H. and Zarit, J. M. (2014) *Supporting families coping with dementia: flexibility and change.* Second edition. In Downs, M. and Bowers, Barbara *Excellence in Dementia Care: Research into Practice*. Maidenhead: Open University Press, 176-189.

Appendix 1 Systematic literature Review

1.1. Critical Appraisal Included Articles

Reference	Beard, R. L., Sakhtah, S., Imse, V., & Galvin, J. E. (2012). Negotiating the joint career: couples adapting to Alzheimer's and aging in place. Journal Of Aging Research, 2012, 797023-797023.
Country of Study	USA
Study Design	Interviews with the couples guided by grounded theory
Sample	N= 20 participants, 6 males with dementia or memory problems and 6 female co-habiting spouse caregivers, 4 females with dementia or memory problems and 4 male co-habiting spouse caregivers. Participants age ranges between 45 and 85+, 9 couples are from a white background and 1 couple is from a Hispanic background, educational levels vary from high school to university degrees, socio-economic status varies from low to upper middle class, living environment varies from urban to rural and the time since the diagnoses varies from 2 years to 5+
Purpose of the Study	Explore the role of the relationship between spouses to adapt to memory loss and aging in place.
Main Findings	Memory loss is not only a negative and isolating experience, and couple hood can give a positive boost creating dignity and value for the spouses and enabling them to age well and live at home longer. This supports current research.
Quality Issues	- There is a lack of reflexivity on the researcher bias, their interaction with participants and personal values and perspectives. - Interview guide/interview questions are missing - The data doesn't give much insight in the aging in place part of the aim. There is no discussion of the relationship of the participants with their home and or environment.

Reference	Bergman, M., Graff, C., Eriksdotter, M., Fugl-Meyer, K., Schuster, M., & Fugl-Meyer, K. S. (2016). The meaning of living close to a person with Alzheimer disease. Medicine, Health Care & Philosophy, 19(3), 341-349.
Country of Study	Sweden
Study Design	Indepth interviews guided by phemonology
Sample	N=10 5 male co-habiting spouse care givers their female spouses with early onset dementia, 5 female co-habiting spouse care givers and heir male spouses with early onset dementia.
Purpose of the Study	Explore the lifeworld of spouses when their partners are diagnosed with early-onset AD. What does it mean to live with a partner with AD?

Main Findings	Daily life with a partner with dementia is difficult and results in a change in ideas about the future. It makes people more aware of their being in the world and confronts them with the fast that the past, present and future are changeable. It may create feeling of being in a space that is “unhomelike”. The lives of the spouses are intertwined and the changes affect them both, changes both their lifeworld.
Quality Issues	- The concept of lifeworld that is central to the interviews and analysis is not adequately explained and operationalized in this context. What is that exact holistic perspective that is guided by this concept? - Interview guide/ interview questions are missing.

Reference	Botsford, J., Clarke, C. L., & Gibb, C. E. (2012). Dementia and relationships: experiences of partners in minority ethnic communities. Journal Of Advanced Nursing, 68(10), 2207-2217.
Country of Study	UK
Study Design	Longditudinal study over 18 months, 43 indepth interviews guided by a construtivist grounded theory approach.
Sample	N=13 co-habiting spouse carers for a partner with dementia, 7 Greek Cypriot spouse carers and 6 Afro Caribean spouse carers, who had been in the UK for at least 45 years. Their age is between late 60’s and 80’s, In long standing partnerships ranging from 22 to 55 years. Spouses had been diagnosed with dementia at least 6 months before the first interview, the degree of dementia varied from mild to severe.
Purpose of the Study	Explores the experiences of African Caribbean and Greek Cypriot partners of people with dementia and contributes to understandings of the impact of ethnic background on the experiences of partners of people with dementia.
Main Findings	- An active process of redefining relationships occurs in the context of having a partner with dementia - Greek Cypriot and African Caribbean people may delay accessing a dementia diagnosis and support. - Ethnic background is important in relation to whether family or formal care is preferred by partners of people with dementia.
Quality Issues	- No information on the gender of the participants. - No Reflexivity on the role of the researcher, researcher bias and their personal ideas, values, believes etc.

Reference	Boyle, G. (2013). 'She's usually quicker than the calculator': financial management and decision-making in couples living with dementia. Health & Social Care in the Community, 21(5), 554-562.
Country of Study	UK
Study Design	Paricipant Observations and Interviews
Sample	N=42 participants, 21 couples, 9 female co-habiting spouse caregivers and their 9 male partners with dementia, 12 male co-

	habiting spouse caregivers and their 12 female partners with dementia. Seven couples were from a working class background and 14 were middle class or upper middle class. The age of the participants varied between 40 and 80.
Purpose of the Study	Examining the role of social factors in influencing the involvement of people with dementia in financial management and decision-making, particulary whether a gender dynamic adopted earlier in a marriage similary influenced a gendered approach following dementia.
Main Findings	- Social factors also influence decision-making in dementia. - People with dementia may be deprived of opportunities for financial decision-making when they still retain this capacity.
Quality Issues	- A weak point is the comparison with decision-making processes within the couple before the onset of the dementia. This is highly speculative since the researcher didn't know the couples before the onset of dementia. This is retrospective and should not be taking into account in the analysis and discussion. - How did the research measure whether a person with dementia still had the ability to take part in the decision making or lacked it? Basing that on only interacting with the spouses in the interviews is highly speculative. This would suggest that the second main finding isn't backed up with enough arguments. - There is a lack of reflexivity on the role of the researcher, researcher bias. - Whether gender can always be an explanatory factor for the role division in a relationship an a couples dynamic is questionable, this could be discussed more. The pre-existing assumptions of the researchers about gendered should be made clear as well as the concept and framework of gender they use in their analysis and discussion otherwise it becomes suggestive and biased. - Observation/interview guide are missing, a topic list would have been a good addition.

Reference	Boyle, G. (2014). 'Can't cook, won't cook': men's involvement in cooking when their wives develop dementia. Journal of Gender studies, 23(4), 336-350.
Country of Study	UK (North England)
Study Design	Observations, photographs and interviews
Sample	N=42, 21 couples, 12 women with Dementia, their male co-habiting spouse carer and 9 men with Dementia and their female co-habiting spouse carer. 7 couples were workingclass and 14 couples were middle and upper middle class.
Purpose of the Study	Explores whether men are willing to cook when their wives develop dementia.

Main Findings	The study demonstrated that gender inequality persists even when women become cognitively disable and it can pose as much a challenge to their agency than their disability.
Quality Issues	- Reflexivity on Researcher own values and believes. - Since the aim of the paper focuses on male spouse caregivers it's questionable why female spouse caregivers are included in the study.

Reference	Brown, J. W., Chen, S.-l., Mitchell, C., & Province, A. (2007). Help-seeking by older husbands caring for wives with dementia. Journal Of Advanced Nursing, 59(4), 352-360.
Country of Study	USA
Study Design	Interviews guided by grounded theory approach
Sample	N= 9 Male co-habiting spousecaregivers for a wife with dementia. Years since diagnoses ranged from 2-13. The men were between 65-87 and their wives between 70-85. Couples had been married between 45-68 years.
Purpose of the Study	Gaining understanding of the help-seeking process of older husbands caring for their wives with dementia.
Main Findings	How attitudes, values, experiences, costs, availability and myriad other conditions worked as hindering and facilitating factors on help-seeking decisions.
Quality Issues	- One of their main findings that male help-seeking behaviour differs from that of women is not supported by the data. There is no discussion on how their help- seeking behaviour differs from women's help-seeking behaviour and how it would be influenced by the position of men in a relationship. No sufficient discussion and proof of how these results can be ascribed to gender. - Interview guide/questions are missing.

Reference	Clare, L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. Aging & Mental Health, 6(2), 139-148.
Country of Study	UK
Study Design	Separate interviews with both the person with dementia and their partner focussed on the perspective of the partner with dementia. Interviews were guided by interpretative phenomenology.
Sample	N=24 of which were 12 people with dementia, 9 men and 3 women with MMSE scores between 19 and 29 (early stages of AD). The partners where 9 women and 3 men. The participants were between 52 and 83 years old.
Purpose of the Study	Exploring in detail the process of adjusting, and to consider a range of ways in which people with early-stage AD try to cope with changes they are experiencing.

Main Findings	All the coping strategy were focussed on finding a positive outcome for the self. It is about finding an equilibrium between hope and despair and about how much someone can adapt to himself and when to accept help. This equilibrium will be shifting as the disease progresses.
Quality Issues	- It doesn't say from which body ethics approval was obtained. - An interview guide is missing.

Reference	Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the martial relationship and Alzheimer's disease: one couple's story. Families, Systems & Health: The Journal of Collaborative Family HealthCare, 25(2), 162-177.
Country of Study	USA
Study Design	A qualitative single-subject case study.
Sample	One co-habiting couple of whom one had dementia and the partner was the carer, they were both in their 80's and had been married for over 63 years. Both had only gone to secondary school and the wife had been a housewife and the husband a manager of an engineering company. The wife had been diagnosed five years before the study.
Purpose of the Study	Understanding more about AD in the context of one couple's relationship.
Main Findings	That topics as family influences, social support, life evaluation, perspectives and preparations for the future and experiences with AD influenced the relationship of the couple and shaped their story together.
Quality Issues	- Although the researchers admit that the sample size is very small and can only describe a specific situation and create awareness I am not sure whether it can really accomplish its aim. It is more descriptive instead of contributing to a deeper understanding.

Reference	Eriksson, H., Sandberg, J., & Hellström, I. (2013). Experiences of long-term home care as an informal caregiver to a spouse: gendered meanings in everyday life for female carers. International Journal Of Older People Nursing, 8(2), 159-165.
Country of Study	Sweden
Study Design	Interviews based on a feminist perspective.
Sample	N=12 Female co-habiting spousal caregivers, between 66 and 80 years old, all from the dominant ethnic group in Sweden.
Purpose of the Study	Exploring the gender aspects of long-term caregiving from the perspective of women providing home care for a spouse who has dementia.

Main Findings	Caregivers reflected in on their caregiving experiences referring to both general and heteronormative expectations. A process of hetero polarisation took place which can be explained by the illness of spouse and the caregiving duties. Also caring leads to introspective evaluation of the shortcomings of the carer. Finally results point out that the need for support is being downplayed by female spouse carers.
Quality Issues	- Interview guide/interview questions missing. - Reflexion on researcher bias and their own perspectives and values. - We could question whether their focus on heteronomy hasn't coloured the data. Has there been enough attention for other possible explanations not gender based?

Reference	Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': spouses' strategies for living positively with dementia. Dementia, 6(3), 383-409.
Country of Study	Sweden
Study Design	Longitudinal, multiple interviews over 5 years time, a total of 152 interviews, guided by a constructivist grounded theory approach.
Sample	N=40, 20 co-habiting couples of whom one has dementia and the partner is spouse caregiver. The sample included 8 females with dementia and their male spouses and 12 males with dementia and their female spouses. The age of the participants ranges from 65 to 85.
Purpose of the Study	Providing renewed insights into the nature of 'couple hood' in dementia.
Main Findings	Framing caring relationships primarily in terms of stress and burden does indeed represent a 'simplistic reductions of the experience that manifestly fails to capture the dynamics of couplehood in dementia.
Quality Issues	- Interview guide is missing - Reflexivity on the role of the researcher, research bias and personal values believes etc. of researcher is missing. - The aim stated in the abstract is different from the aim stated in the article.

Reference	Jansson, W., Nordberg, G., & Grafström, M. (2001). Patterns of elderly spousal caregiving in dementia care: an observational study. Journal Of Advanced Nursing, 34(6), 804-812.
Country of Study	Sweden
Study Design	Observations guided by grounded theory.
Sample	N=8 , all co-habiting spouse caregivers of spouses with dementia in different stages. The age ranges from 69 to 85.

Purpose of the Study	Describing which caring activities eight spouses performed when caring for a partner with dementia, and in what way these activities were carried out.
Main Findings	All caregivers shared remarkable similarities in the way that they performed the caring role. Important themes were, the full-time responsibility of caring, having to scarify some of their own needs, offering help in all the activities of the spouse and being constantly tied to the caregiving. On top of that spouses were mediators between their spouse other family members and social and health care networks.
Quality Issues	- Lack of observation guide. - No reflexivity on the values, ideas, perceptions etc. of the researchers.

Reference	Murray, J., Schneider, J., Banerjee, S., & Mann, A. (1999). EUROCARE: a crossnational study of co-resident spouse carers for people with Alzheimer's disease: II--A qualitative analysis of the experience of caregiving. International Journal Of Geriatric Psychiatry, 14(8), 662-667.
Country of Study	Europe 14 Different states
Study Design	Semi-structured interviews
Sample	N=280 co-habiting spousecarers for someone with AD.
Purpose of the Study	Exploring whether there are qualitative differences in the experiences of carers who live in countries with statutory right to support and those who are bound by duty to care and whether there are gender differences.
Main Findings	The analysis reveals a consistency in the subjective experiences of husbands and wives caring for people with dementia across the EU.
Quality Issues	- Lack of information on methods and design, for example there is no interview guide included. Supposedly this information is reported elsewhere. - No reflexivity on the role of the researcher, researcher bias and researchers own believes/values, etc.

Reference	Paun, O. (2003). Older women caring for spouses with Alzheimer's disease at home: making sense of the situation. Health Care for Women International, 24(4), 292-312.
Country of Study	USA
Study Design	One in depth interview with each participant guided by a phemonological and feminist approach
Sample	N=14 female co-habiting spouse caregivers, 5 African American women and 9 Caucasian women. One of them was Jewish and the others were Christians. Their socio-economic position varied from low to upper middle class. They all had been been caregivers for at least three years.

Purpose of the Study	- To document and explore the experience of caregiving from the perspective of older women who are taking care at home of a spouse diagnosed with AD. - To gain a clearer and profound understanding of what it means to be an older women AD caregiver.
Main Findings	They acknowledged their losses and counted their blessings, keeping a positive outlook on the situation. And they made it clear that it was their choice to care for their spouse at home and were determined to keep doing so as long as possible, holding on to the marriage both in case of a fulfilling and difficult marriage.
Quality Issues	The study might not be able to fulfil the aim of gaining a clear and profound understanding of what it means to be an older women with dementia. Only one interview with each participant will not give you such a deep understanding. Some of the findings on how women felt in the specific situations are a bit speculative.

Reference	Shim, B., Barroso, J., Gilliss, C. L., & Davis, L. L. (2013). Finding meaning in caring for a spouse with dementia. Applied Nursing Research: ANR, 26(3), 121-126.
Country of Study	USA
Study Design	Semi-Structured interviews guided by naturalistic inquiry
Sample	N=11 Co-habiting spouse carers of a partner with dementia. Five male and six female carers, ten of them were from Caucasian background and one was from African American Background. All of them were Chrisitians and from a variety of socio-economic backgrounds.
Purpose of the Study	To investigate how spousal caregivers of individuals with dementia found personal meaning in their caregiving experience.
Main Findings	Although the experiences, circumstances and situation of the caregivers varied they all responded in a similar way to the questions. They were all determined to live by the values they believed in. Their values and ethics were the basis for the decisions they made. Upholding these believes they created self-worth and gave meaning to their experiences.
Quality Issues	- Interview guide ,interview questions are missing - No reflexion on researcher bias, their personal believes

Reference	Vikström, S., Borell, L., Stigsdotter-Neely, A., & Josephsson, S. (2005). Caregivers' self-initiated support toward their partners with dementia when performing an everyday occupation together at home. OTJR: Occupation, Participation & Health, 25(4), 149-159.
Country of Study	Sweden
Study Design	Observations using video of couples making afternoon tea guided by a constant comparative approach.

Sample	N=60 participants, 30 co-habiting spouses of whom one has mild to moderate dementia and the partner is the caregiver. It included 14 male caregivers and their 14 wives with dementia and 16 female caregivers with their 16 male husbands. There is socio-economic variation in the sample based on a variation in education levels.
Purpose of the Study	Identify the support caregivers provide by their own initiative when performing an everyday occupation together with their partner who has dementia.
Main Findings	There are two major themes related to the support spouses provided: provision of a supportive climate and provision of practical support.
Quality Issues	- No reflexivity on researcher bias, their role and their own values, assumptions, etc. - They state later on in the paper that they use a participant observation approach while they clearly only used observations.

Reference	Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities: experiences of persons with dementia and their caregiving spouses. Dementia 7 (2), 251-270.
Country of Study	Sweden
Study Design	Semi-structured interviews and a qualitative constant comparative analysis
Sample	N=52, 26 co-habiting couples. All participants were between 59 and 86 years old and there is socio-economic variation in the couples.
Purpose of the Study	This study identifies how persons with dementia and their caregiving spouses individually perceive their self, their spouse and their mutual engagement in daily activities.
Main Findings	The caregiving spouse will experience dilemmas which are related to power balance and their own and their spouse's needs.
Quality Issues	- The interview guide is missing - No reflexivity on the role of the researcher, researcher bias, and the researchers own perceptions, believes etc.

Reference	Walters, A. H., Oyebode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. Dementia, 9(2), 169-189.
Country of Study	UK
Study Design	Semi-structured interviews guided by a grounded theory approach.
Sample	N=6 co-habiting Female carers of a spouses with dementia. Between 64 and 78 years old having been married for between 19 and 58 years.
Purpose of the Study	Explores spouse caregivers understanding of and responses to partners with dementia.
Main Findings	Participants sense of continuity was suggested to be important in the understanding and response to the partner having dementia. A sense

	of continuity seemed to be associated with a better adjustment to caregiving.
Quality Issues	- How were the participants recruited? - Where were the participants recruited? - How was reflexivity used in this study?

1.1.1 Update Systematic synthesis 24/07/2018

Reference	Sinclair, Craig, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar, and Sue Kurrle. 2018. "How couples with dementia experience healthcare, lifestyle, and everyday decision-making." *International Psychogeriatrics*:1-9.
Country of Study	Australia
Study Design	Semi-structured qualitative interviews using Interpretative Phenomenological Analysis as the methodological approach (Sinclair et al. 2018:1).
Sample	Twenty-eight participants who self-identified as being in a close and continuing relationship (*N* = 13 people with dementia, *N* = 15 spouse partners). Nine couples were interviewed together (Sinclair et al. 2018:1).
Purpose of the Study	The aim of the study was to understand the lived experiences of couples living with dementia, with respect to healthcare, lifestyle, and "everyday" decision-making (Sinclair et al. 2018:1).
Main Findings	Participants described a spectrum of decision-making approaches (independent, joint, supported, and substituted), with these approaches often intertwining in everyday life. Couples' approaches to decision making were influenced by "decisional," "individual," "relational," and "external" factors. The overarching themes of "knowing and being known," "maintaining and re-defining couplehood" and "relational decision-making,"re used to interpret these experiences. The spousal relationship provided an important context for decision-making, with couples expressing a history and ongoing preference for joint decision-making, as an integral part of their experience of couplehood. However, the progressive impairments associated with dementia presented challenges to maintaining joint decision-making and mutuality in the relationship. This study illustrates relational perspectives on decision-making in couples with dementia. Post diagnostic support, education resources, proactive dyadic interventions, and assistance for spouse care partners may facilitate more productive attempts at joint decision-making by couples living with dementia (Sinclair et al. 2018:1).
Quality Issues	- Lack of reflexivity on the relationship between the researchers and participants. - Interview questions not included in article.

1.2 Articles Exclusion Round 3 Critical Appraisal

Reference	Clare, L., & Shakespeare, P. (2004). Negotiating the Impact of Forgetting Dimensions of Resistance in Task-Oriented Conversations between People with Early-Stage Dementia and their Partners. Dementia, 3(2), 211-232.
Country of Study	UK
Study Design	Qualitative investigation of conversational interactions between people with early-stage dementia and their partners.
Sample	N=20, 10 couples of whom one has dementia and the partner is the spouse carer. 8 men and 2 women with dementia and 8 female and 2 male spouse carers. Age ranged from 52 to 83. And the minimum MMSE score to be included in the project was 18, the scores of the people with dementia ranged from 20 to 29. All participants were from white European background and from a variation of socio-economic backgrounds.
Purpose of the Study	Investigating conversational interactions between people with early-stage dementia and their spouses.
Main Findings	The conversations demonstrate the complexities imposed on the already intricate web of relationship by the added dimension of 'forgetting' and the societal and cultural meaning this carries.
Quality Issues	- Analysing language use might not be an appropriate method when people are cognitively impaired, speech and word finding can be impaired too. The selection criteria based on MMSE score doesn't necessarily control for speech and word finding impairment as it is just a test that dont include peoples full vocabulary. - The researchers don't know what the conversation dynamic of the couple was before the onset of dementia. They might be ascribing part of the dynamic to dementia while this already existed. - On top of that does this research seem more suitable for a experimental setting with a control group. - Five minutes of conversation which is giving as a task/assignment seems too short to entangle the natural conversation dynamic of the couple. - Especially this kind of study should elaborate on reflexivity, validity and rigour. None of these topics are addressed. The research method doesn't seem the right one to accomplish the aim. On top of that there is a lack of critical thinking about how the study is designed and its implications on the validity and rigour of the results, as a result of this the study has been excluded from the systematic review.

Reference	Hellström, I., Nolan, M., & Lundh, U. (2005). 'We do things together' A case study of 'couplehood'in dementia. Dementia, 4(1), 7-22.
Country of Study	Sweden
Study Design	Longitudinal study over 18 months, 4 separate interviews with the person living with dementia and the co-habiting caregiving spouse.
Sample	N=2, 1 couple of whom one lives with dementia and the co-habiting caregiving spouse
Purpose of the Study	Presenting a case study of an elderly married couple living with dementia and explore how their relationship has continued to flourish
Main Findings	That this case study describes why there should me a focus on 'couple hood' in further research.
Quality Issues	- No reflexivity on researcher role, researcher bias and the personal values and believes, etc. of the researcher - The paper in general has an aim that is biased, looking at how the relationship has continued to flourish which form the start puts the analysis towards finding arguments to prove the importance of relationships - The aim that seems to be in explicit in this article seems to advocate a discourse change into a relationship focused approach in dementia care. - This study is serves a week argument to push that change in discourse being based on a single case study and only four interviews to sketch a picture of a couple's relationship combined with the lack of reflexivity the validity is questionable. - On top of that this paper uses a misinterpretation of the discourse around personhood to push its own discourse. This make the argument of this study even weaker. It argues that personhood is based on the individual and dismisses relationship perspectives. This is not true the personhood discourse might be centred around the individual with dementia but to accomplish the acknowledgement of the personhood it argues that relationships with the person with dementia need to acknowledge and stimulate the personhood. It's main focus might not be the relationship but it certainly doesn't only focus on the individual. Overall the aim of presented in the study doesn't seem to fit the message of the article. On top of that is the argumentation of for its message weak and can the research methods and sample size be criticised. Too many quality issues to include this article in the literature review.

Reference	Hellström, I., & Torres, S. (2014). "The not yet" horizon: Understandings of the future amongst couples living with dementia. Dementia (London, England)
Country of Study	Sweden

Study Design	Interviews with people with dementia and their co-habiting spouses.
Sample	N=40 of whom 20 people had dementia, and they were all able to express themselves.
Purpose of the Study	Explore how the future is understood by couples living with dementia.
Main Findings	The study revealed five different patterns in which couples understand the future. Divided in the couples who agreed on an outlook on the future and the couples who didn't.
Quality Issues	- Analysing language use might not be an appropriate method when people are cognitively impaired, speech and word finding can be impaired too. - No reflexion has been made on a possible translation bias and how to control for it. - Lack of reflexivity on role of the researcher, researcher bias and personal values, believes etc. - Interview guide/questions are missing - Small sample and no diversity in the sample, the diversity might be too small to develop a typology of trajectories. - Developing this typology based on different phases of the dementia measured by a FAST scale is a questionable method since the we know that the scores on a scale like that are not always representative of the actual stage of the dementia and the personal experience and abilities which are not measured by the scale. Overall I am not convinced that the supposed methods are able to explore how couples living with dementia understand the future because it's possible limitation caused by the analysis of language. On top of that the other quality issues are concerning.

Reference	Hydén, L.-C., & Nilsson, E. (2015). Couples with dementia: Positioning the 'we'. Dementia (London, England), 14(6), 716-733.
Country of Study	Sweden
Study Design	Joint interviews with the couples, a quantitative analysis of the use of pronounce was used.
Sample	N= 22 , 11 couples of whom one has dementia and the spouse is the caregiver. The MMSE test results of the participants with dementia ranged from 22 to 29. The years of being diagnosed varied from a year to four years. The age of the participants varied between 57 and 86 the duration of their relationship varied between 12 and 60 years.
Purpose of the Study	Investigate how spouses in couples with dementia position themselves in relation to each other by analysing their use of pronouns, especially the 'we'.
Main Findings	People with dementia are not only socially responsive but actually sometimes actively structure their relationship with their spouses in quite complex ways.

Quality Issues	- Frist of all can be questioned whether this research is quantitative since the analysis of the pronounce is. In that case this study should be excluded based on the quantitative design. - Analysing language use might not be an appropriate method when people are cognitively impaired, speech and word finding can be impaired too. - It is not well argued why the use of we should be an indication of the positioning of spouses in a relationship. - Not sure if this research method is capable of reaching it's aim. - Lack of reflexivity on role of the researcher, researcher bias and personal values, believes etc. Because it is questionable whether the research methods are valid and accomplish its aim this article is excluded from the systematic review.

Reference	Kuppuswamy, M., Davies, H. D., Spira, A. P., Zeiss, A. M., & Tinklenberg, J. R. (2007). Sexuality and intimacy between individuals with Alzheimer's disease and their partners: Caregivers describe their experiences. Clinical Gerontologist, 30(3), 75-81.
Country of Study	USA
Study Design	Structured interviews
Sample	N=50 caregivers, 38 women and 12 men
Purpose of the Study	Provide a description of caregivers' experiences with, and emotional responses to, changes in their sexual relationships with aprtners, diagnosed with AD.
Main Findings	A diversity in responses, anger, denail, statisfaction, humor, fantasy.
Quality Issues	- The discussion of the results is very limited. The results are barely presented and discussed. - Study design is not well presented and explained - The method of analysis is not discussed The lack of this basic information about the study makes it unable to include the study in the literature review.

1.2.1 Update systematic synthesis 24/07/2018

Reference	McGovern, Justine. 2017. "Capturing the significance of place in the lived experience of dementia." *Qualitative Social Work* 16 (5):664-679.
Country of Study	USA
Study Design	Ethnographic thick description combined with Phenomenological participant observation and Grounded Theory prolonged engagement and data analysis based on naturalistic inquiry. She visited seven couples for a month and conducted interviews, did observation and analysed documents and objects presented to her by participants.
Sample	N=14, 7 couples of whom one has got dementia and who lived together in the Metropolitan area of New York. All participants were over 64
Purpose of the Study	Linking the significance of place with the quality of life for couples of whom one has got dementia and the partner is the primary carer. And showing that data collection methods other than interviews would work well in dementia care research (creative methods).
Main Findings	The home environment works as a confirmation of the relationship of the couple, the memories of the space in which they have lived together for a long time and still live create 'we-ness'. Furthermore, having neighbours around that are able to help out with tasks and care and offer recreational activities can be beneficial to the couple. Lastly having amenities at a walking distance can help to keep up a daily routine and autonomy of the couple.
Quality Issues	- The aim is to connect the significance of space to the quality of life of the couple but there is no clear definition of quality of life in the article. - The methods of both data collection and analysis are not the right methods to measure or analyse quality of life. It are explorative descriptive methods. - The data collection methods are confusion, ethnography, phemenology and grounded theory? Why not chose one approach, in all approaches there would have been room for all methods. It does not become clear why this combination of approaches is used. It becomes further confusing when the author speaks of theoretical triangulation based on phenomenology, social constructivism and getrotransdence. But she does not explain why this is theory triangulation and how these theories connected to the data collection and data analysis methods. - Thematic analyses without connecting the data to the concept of quality of life.

	- There is a section on dementia and the global context in the article. I do not understand how this context connects to the message of the article it is not clear. Although the data presented in the study is rich and interesting the methodological background of the study is too confusing and the lack of a clear definition of quality of life and how it connects to the results make the results not very convincing. The aim of the article has not been completed.

1.3 Articles Exclusion Round 2 Exclusion Criteria

References	Exclusion Criteria
Abdo, C. H. N. (2013). Sexuality and couple intimacy in dementia. Current Opinion In Psychiatry, 26(6), 593-598.	Review
Ahmed, R. M., Kaizik, C., Irish, M., Mioshi, E., Dermody, N., Kiernan, M. C., Hodges, J. R. (2015). Characterizing Sexual Behavior in Frontotemporal Dementia. *Journal Of Alzheimer's Disease: JAD, 46*(3), 677-686. doi:10.3233/JAD-150034	Quantitative Methods and or Design
Ascher, E. A., Sturm, V. E., Seider, B. H., Holley, S. R., Miller, B. L., & Levenson, R. W. (2010). Relationship satisfaction and emotional language in frontotemporal dementia and Alzheimer disease patients and spousal caregivers. Alzheimer Disease And Associated Disorders, 24(1), 49-55.	Quantitative methods and or design
Baikie, E. (2002). The impact of dementia on marital relationships. Sexual & Relationship Therapy, 17(3), 289-299.	Review
Bakker, C., de Vugt, M. E., van Vliet, D., Verhey, F. R. J., Pijnenburg, Y. A., Vernooij-Dassen, M. J. F. J., & Koopmans, R. T. C. M. (2013). The use of formal and informal care in early onset dementia: results from the NeedYD study. The American Journal Of Geriatric Psychiatry: Official Journal Of The American Association For Geriatric Psychiatry, 21(1), 3745.	Includes other family carers other than spouse carers
Barusch, A. S., & Spaid, W. M. (1996). Spouse caregivers and the caregiving experience: does cognitive impairment make a difference? Journal of Gerontological Social Work, 25(3/4), 93-105.	Includes other family carers other than spouse carers
Ballard, C. G., Solis, M., Gahir, M., Cullen, P., George, S., Oyebode, F., et al. (1997). Sexual relationships in married dementia sufferers. International Journal Of Geriatric Psychiatry, 12(4), 447-451.	Biomedical or Psychosocial Focus

Batt-Leiba, M. I., Hills, G. A., Johnson, P. M., & Bloch, E. (1998). Implications of coping strategies for spousal caregivers of elders with dementia. Topics in Geriatric Rehabilitation, 14(1), 54-62	Biomedical or Psychosocial Focus
Bauer, M. J., Maddox, M. K., Kirk, L. N., Burns, T., & Kuskowski, M. A. (2001). Progressive dementia: personal and relational impact on caregiving wives. American Journal of Alzheimer's Disease & Other Dementias, 16(6), 329-334.	Biomedical or Psychosocial Focus
Benbow, S. M., & Jagus, C. E. (2002). Sexuality in older women with mental health problems. Sexual & Relationship Therapy, 17(3), 261-270.	Includes spouse carers of partners who don't have dementia
Benbow, S. M., & Kingston, P. (2016). 'Talking about my experiences…at times disturbing yet positive': Producing narratives with people living with dementia. Dementia (London, England), 15(5), 1034-1052.	Includes other family carers other than spouse carers
Bergman-Evans, B. F. (1994). Alzheimer's and related disorders: loneliness, depression, and social support of spousal caregivers. *Journal of Gerontological Nursing*, 6-16.	Situated in institutionalized care
Betts Adams, K., McClendon, M. J., & Smyth, K. A. (2008). Personal losses and relationship quality in dementia caregiving. Dementia, 7(3), 301-319.	Biomedical or Psychosocial Focus
Borden, W., & Berlin, S. (1990). Gender, coping, and psychological well-being in spouses of older adults with chronic dementia. The American Journal Of Orthopsychiatry, 60(4), 603-610.	Biomedical or Psychosocial Focus
Boucher, L., Renvall, M. J., & Jackson, J. E. (1996). Cognitively impaired spouses as primary caregivers for demented elderly people. Journal of the American Geriatrics Society, 44(7), 828-831.	Quantitative methods and or design
Boutayeb, A., Boutayeb, S., & Boutayeb, W. (2013). Multi-morbidity of non communicable diseases and equity in WHO Eastern Mediterranean countries. International Journal for Equity in Health, 12(1).	Review
Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: a dyadic perspective. Aging & Mental Health, 13(3), 426-436.	Review
Brown, L. J., & Bond, M. J. (2016). Transition from the spouse dementia caregiver role: A change for the better? Dementia (London, England), 15 (4), 756-773.	Biomedical or Psychosocial Focus
Bruce, J. M., McQuiggan, M., Williams, V., Westervelt, H., & Tremont, G. (2008). Burden among spousal and child caregivers of patients with mild cognitive impairment. Dementia and Geriatric Cognitive Disorders, 25(4), 385-390	Biomedical or Psychosocial Focus

Buffum, M. D., & Brod, M. (1998). Humor and well-being in spouse caregivers of patients with Alzheimer's disease. Applied Nursing Research, 11(1), 12-18.	Quantitative methods and or design
Burton, C. A., & Sistler, A. B. (1996). A note on whether spousal caregivers try to control their environment or themselves. The Journal of psychology, 130(4), 421-427.	Quantitative methods and or design
Butt, Z. A., Strauss, M. E., Smyth, K. A., & Rose-Rego, S. K. (2002). Negative affectivity and emotion-focused coping in spouse caregivers of persons with Alzheimer's disease. Journal of Applied Gerontology, 21(4), 471483.	Quantitative methods and or design
Buttell, F. P. (1999). The relationship between spouse abuse and the maltreatment of dementia sufferers by their caregivers. American Journal of Alzheimer's Disease, 14(4), 230-232.	Review
Campell, D. D., & Travis, S. S. (1999). Spousal caregiving when the adult day services center is closed. *Journal Of Psychosocial Nursing And Mental Health Services, 37*(8), 20-25	Quantitative methods and or design
Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. Canadian Journal On Aging = La Revue Canadienne Du Vieillissement, 33(4), 462-472.	Includes other family carers other than spouse carers
Chatterji, R. (1998). An ethnography of dementia. Culture, Medicine And Psychiatry, 22(3), 355-382.	Situated in institutionalized care
Cipriani, G., Ulivi, M., Danti, S., Lucetti, C., & Nuti, A. (2016). Sexual disinhibition and dementia. Psychogeriatrics: The Official Journal Of The Japanese Psychogeriatric Society, 16(2), 145-153.	Review

References	**Exclusion Criteria**
Clare, L., & Shakespeare, P. (2004). Negotiating the Impact of Forgetting Dimensions of Resistance in Task-Oriented Conversations between People with Early-Stage Dementia and their Partners. Dementia, 3(2), 211-232.	Quantitative methods and or design
Clark, M. S., & Bond, M. J. (2000). The effect on lifestyle activities of caring for a person with dementia. Psychology, Health & Medicine, 5(1), 13-27.	Quantitative methods and or design
Collins, C., & Jones, R. (1997). Emotional distress and morbidity in dementia carers: A matched comparison of husbands and wives. International Journal of Geriatric Psychiatry, 12(12), 1168-1173.	Quantitative methods and or design
Commissaris, C. J. A. M., Jolles, J., Verhey Jr, F. R. J., & Kok, G. J. (1995). Problems of caregiving spouses of patients with dementia. Patient Education and Counseling, 25(2), 143-149.	Quantitative methods and or design

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Quality of life of patients with Alzheimer's disease: differential perceptions between spouse and adult child caregivers. Dementia And Geriatric Cognitive Disorders, 29(2), 97-108.	Includes other family carers other than spouse carers
Connell, C. M. (1994). Impact of spouse caregiving on health behaviors and physical and mental health status. American Journal of Alzheimer's Disease and Other Dementias, 9(1), 26-36.	Biomedical or Psychosocial Focus
Connell, C. M., Janevic, M. R., Solway, E., & McLaughlin, S. J. (2007). Are pets a source of support or added burden for married couples facing dementia? Journal of Applied Gerontology, 26(5), 472-485.	Quantitative methods and or design
Coste, J. K. (2004). The ticking meter. American Journal Of Alzheimer's Disease And Other Dementias, 19(5), 316-318.	Autobiographic
Cox, C. B., & Albisu, K. (2003). The impact of caregiving for a relative with Alzheimer's disease: a comparison of those caring for persons living alone, spousal caregivers, and co-resident adult children. Journal of Mental Health & Aging, 23-33.	Includes other family carers other than spouse carers
Davies, J., & Gregory, D. (2007). Entering the dialogue: marriage biographies and dementia care. Dementia (14713012), 6(4), 481-488.	Intervention
Davies, H. D., Newkirk, L. A., Pitts, C. B., Coughlin, C. A., Sridhar, S. B., Zeiss, L. M., et al. (2010). The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships. International Psychogeriatrics / IPA, 22(4), 618-628	Includes spouse carers of partners who don't have dementia
Davies, H. D., Sridhar, S. B., Newkirk, L. A., Beaudreau, S. A., & O'Hara, R. (2012). Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being. Aging & Mental Health, 16 (1), 89-101.	Quantitative methods and or design
Davies-Abbott, I., & MacDonald, K. (2012). Supporting relationships. Journal of Dementia Care, 20(5), 10-11.	Intervention
Davies, H. D., Zeiss, A. M., Shea, E. A., & Tinklenberg, J. R. (1998). Sexuality and intimacy in Alzheimer's patients and their partners. Sexuality & Disability, 16(3), 193-203.	Intervention
Davies, H. D., Zeiss, A., & Tinklenberg, J. R. (1992). 'Til death do us part: intimacy and sexuality in the marriages of Alzheimer's patients. *Journal of Psychosocial Nursing & Mental Health Services, 30*(11), 5-36.	Situated in institutionalized care
Davis, L. L., Chestnutt, D., Molloy, M., Deshefy-Longhi, T., Shim, B., & Gilliss, C. L. (2014). Adapters, Strugglers, and Case Managers: A Typology of Spouse Caregivers. Qualitative Health Research, 24(11), 1492-1500.	Includes spouse carers of partners who don't have dementia

de Vugt, M. E., Jolles, J., van Osch, L., Stevens, F., Aalten, P., Lousberg, R., & Verhey, F. R. J. (2006). Cognitive functioning in spousal caregivers of dementia patients: Findings from the prospective MAASBED study. Age and Ageing, 35(2), 160-166.	Quantitative methods and or design
De Vugt, M. E., Riedijk, S. R., Aalten, P., Tibben, A., Van Swieten, J. C., & Verhey, F. R. J. (2006). Impact of behavioural problems on spousal caregivers: A comparison between Alzheimer's disease and frontotemporal dementia. Dementia and Geriatric Cognitive Disorders, 22 (1), 35-41.	Biomedical or Psychosocial Focus
De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. International Journal of Geriatric Psychiatry, 18(2), 149-154.	Biomedical or Psychosocial Focus
DeJarnette, T. M. (1998). Advance directives are important for unmarried couples. Faculty Notes (New Orleans, La.), 10(1), 7-7.	Focused only on decision making
DiBartolo, M. C., & Soeken, K. L. (2003). Appraisal, coping, hardiness, and self-perceived health in community-dwelling spouse caregivers of persons with dementia. Research In Nursing & Health, 26(6), 445-458.	Quantitative methods and or design
Dixon, M., & Curtis, L. (2013). Knowing and telling about dementia: Supporting couples to go on together following diagnosis. Clinical Psychology Forum (250), 32-36.	Formal Care Support ;form the Formal Care Perspective
Draper, B., & Cole, A. (1990). Folie à deux and dementia. The Australian And New Zealand Journal Of Psychiatry, 24(2), 280-282.	Biomedical or Psychosocial Focus
Draper, B., & Withall, A. (2016). Young onset dementia. Internal Medicine Journal, 46(7), 779-786.	Formal Care Support form; the Formal Care Perspective
Draper, B. M., & Draper, B. M. (2009). Richard Mahony - the misfortunes of younger onset dementia. Medical Journal of Australia, 190(2), 94-95.	Review
Ducharme, F., Kergoat, M.-J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. American Journal Of Alzheimer's Disease And Other Dementias, 28(6), 634-641.	Quantitative methods and or design
Ehrenfeld, M., Tabak, N., Bronner, G., & Bergman, R. (1997). Ethical dilemmas concerning sexuality of elderly patients suffering from dementia. International Journal Of Nursing Practice, 3(4), 255-259.	Situated in institutionalized care

References	Exclusion Criteria
Ellman, M. S. (2008). When is the Reverend coming? Patient Education And Counseling, 73(1), 6-7.	Formal Care Support ;form the Formal Care Perspective
Ellsberg, M., Jansen, H. A. F. M., Heise, L., Watts, C. H., & Garcia-Moreno, C. (2008). Intimate partner violence and women's physical and mental health in the WHO multi-country study on women's health and domestic violence: an observational study. Lancet (London, England), 371(9619), 1165-1172.	Not focused on Dementia and or Memory Problems and or Alzheimers
Eloniemi-Sulkava, U., Notkola, I., Hämäläinen, K., Rahkonen, T., Viramo, P., Hentinen, M., et al. (2002). Spouse caregivers' perceptions of influence of dementia on marriage. International Psychogeriatrics, 47-58.	Quantitative methods and or design
Elul, E. B. (2014). The Place We Call Home. Interactions, 21(1), 62.	Not focused on Dementia and or Memory Problems and or Alzheimers
Evans, S. (2004). Sex and death: The ramifications of illness and aging in older couple relationships. Sexual and Relationship Therapy, 19(3), 319-335.	Focussed on Research Methods
Fisher, L., & Lieberman, M. A. (1994). Alzheimer's disease: the impact of the family on spouses, offspring, and inlaws. Family Process, 33(3), 305-325.	Includes other family carers other than spouse carers
Fitting, M., Rabins, P., Lucas, M. J., & Eastham, J. (1986). Caregivers for dementia patients: a comparison of husbands and wives. The Gerontologist, 26(3), 248-252.	Biomedical or Psychosocial Focus
Fitzpatrick, K. E., & Vacha-Haase, T. (2010). Marital satisfaction and resilience in caregivers of spouses with dementia. Clinical Gerontologist, 33(3), 165-180	Quantitative methods and or design
Fjellström, C., Starkenberg, A., Wesslén, A., Licentiate, M. S., Tysén Bäckström, A.-C., & Faxén-Irving, G. (2010). To be a good food provider: an exploratory study among spouses of persons with Alzheimer's disease. American Journal Of Alzheimer's Disease And Other Dementias, 25(6), 521-526.	Includes other family carers other than spouse carers
Forbes, D. (2002). Training family care givers of people with dementia to think in a more clinical manner decreased depression and the sense of burden. Evidence Based Nursing, 21-21.	Controlled Trial
Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). 'Her world gets smaller and smaller with nothing to look forward to': dimensions of social inclusion and exclusion among rural dementia care networks.	Includes other family carers other than spouse carers

Online Journal of Rural Nursing & Health Care, 11(2), 27-42.	
Forbes, D. A., Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. Rural & Remote Health, 12(4), 1-15.	Formal Care Support ;form the Formal Care Perspective
Forbes, D. A., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., et al. (2008). Availability and acceptability of Canadian home and community-based services: perspectives of family caregivers of persons with dementia. Home Health Care Services Quarterly, 27(2), 75-99.	Includes other family carers other than spouse carers
Ford, J. L., Linde, B. D., Gigliotti, C., & Kim, K. Y. (2013). Grief experiences of 3 caregiving wives of veterans with dementia. The American Journal Of Hospice & Palliative Care, 30(2), 137-145.	Quantitative methods and or design
Garand, L., Dew, M. A., Eazor, L. R., DeKosky, S. T., Reynolds, C. F., Garand, L., Reynolds, C. F., 3rd. (2005). Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive Impairment. International Journal of Geriatric Psychiatry, 20(6), 512-522.	Biomedical or Psychosocial Focus
Garand, L., Dew, M. A., Urda, B., Lingler, J. H., DeKosky, S. T., & Reynolds, C. F., III. (2007). Marital quality in the context of mild cognitive impairment. Western Journal of Nursing Research, 29(8), 976-992.	Quantitative methods and or design
Garner, J. (1997). Dementia: an intimate death. The British Journal Of Medical Psychology, 70 (Pt 2), 177-184.	Intervention
Gold, D. P., Franz, E., Reis, M., & Senneville, C. (1994). The influence of emotional awareness and expressiveness on care-giving burden and health complaints in women and men. Sex Roles, 31(3-4), 205-224.	Quantitative methods and or design
Golden, M. A., & Lund, D. A. (2005). Positioning in a support group for spouses of persons with dementia. International Journal of Self Help & Self Care, 4(1-2), 121-136.	Formal Care Support ;form the Formal Care Perspective
Gruetzner, H., Ellor, J. W., & Back, N. (2012). Identifiable Grief Responses in Persons With Alzheimer's Disease. Journal of Social Work in End-of-Life & Palliative Care, 8(2), 151-164.	Intervention
Guay, D. R. (2008). Inappropriate sexual behaviors in cognitively impaired older individuals. American Journal of Geriatric Pharmacotherapy, 6(5), 269-288.	Controlled Trial

Haddad, P. M., & Benbow, S. M. (1993). Sexual problems associated with dementia: Part 1. Problems and their consequences. [Article]. International Journal of Geriatric Psychiatry, 8(7), 547-551.	Review
Hanks, N. (1992). The effects of Alzheimer's Disease on the sexual attitudes and behaviours of married caregivers and their spouses. Sexuality and Disability, 10(3), 137-151.	Intervention
Hanson, C. D., & Clarke, C. (2013). Is expressed emotion related to estimates of ability made by older people with cognitive impairments and their partners? Aging & Mental Health, 17(5), 535-543.	Biomedical or Psychosocial Focus
Harper, S., & Lund, D. A. (1990). Wives, husbands, and daughters caring for institutionalized and noninstitutionalized dementia patients: toward a model of caregiver burden. International Journal Of Aging & Human Development, 30(4), 241-262.	Intervention Focused on Research Methods
Harris, S. M., Adams, M. S., Zubatsky, M., & White, M. (2011). A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. Aging & Mental Health, 15(8), 950-960.	Review
Hartmans, C., Comijs, H., & Jonker, C. (2014). Cognitive functioning and its influence on sexual behavior in normal aging and dementia. International Journal Of Geriatric Psychiatry, 29(5), 441-446.	Quantitative methods and or design

References	**Exclusion Criteria**
Häusler, A., Sánchez, A., Gellert, P., Deeken, F., Rapp, M. A., & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses: does dyadic coping matter? International Psychogeriatrics / IPA, 1-10	Biomedical or Psychosocial Focus
Hepburn, K., Lewis, M. L., Narayan, S., Tornatore, J. B., Bremer, K. L., & Sherman, C. W. (2002). Discourse-derived perspectives: differentiating among spouses' experiences of caregiving. American Journal of Alzheimer's Disease & OtherDementias, 17(4), 213-226.	Quantitative methods and or design
Hendryx-Bedalov, P. M. (1999). Effects of caregiver communication on the outcomes of requests in spouses with dementia of the Alzheimer type. International Journal Of Aging & Human Development, 49(2), 127-148.	Quantitative methods and or design
Hendy, K. (2010). Exceptional work. Nursing Standard, 24(41), 18-19.	Autobiographical
Herron, R. V., & Rosenberg, M. W. (2016). "Not there yet": Examining community support from the	Includes other family carers other

perspective of people with dementia and their partners in care. Social Science & Medicine (1982), 173, 81-87.	than spouse carers
Hong, S.-C., & Coogle, C. L. (2016). Spousal Caregiving for Partners With Dementia: A Deductive Literature Review Testing Calasanti's Gendered View of Care Work. Journal Of Applied Gerontology: The Official Journal Of The Southern Gerontological Society, 35(7), 759-787.	Review
Hooker, K., Frazier, L. D., & Monahan, D. J. (1994). Personality and coping among caregivers of spouses with dementia. Gerontologist, 34(3), 386-392.	Biomedical or Psychosocial Focus
Hooker, K., Monahan, D. J., Bowman, S. R., Frazier, L. D., & Shifren, K. (1998). Personality counts for a lot: predictors of mental and physical health of spouse caregivers in two disease groups. The Journals Of Gerontology. Series B, Psychological Sciences And Social Sciences, 53(2), P73-P85.	Biomedical or Psychosocial Focus
Hopper, T., & Hinton, P. (2012). Hearing Loss among Individuals with Dementia: Barriers and Facilitators to Care. Canadian Journal of Speech-Language Pathology & Audiology, 36(4), 302-313.	Review
Häusler, A., Sánchez, A., Gellert, P., Deeken, F., Rapp, M. A., & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses: does dyadic coping matter? International Psychogeriatrics / IPA, 1-10.	Biomedical or Psychosocial Focus
Kaiser, S., & Panegyres, P. K. (2006). The psychosocial impact of young onset dementia on spouses. American Journal of Alzheimer's Disease & Other Dementias, 21(6), 398-402.	Biomedical or Psychosocial Focus
Kapust, L. R. (1982). Living with dementia: the ongoing funeral. Social Work In Health Care, 7(4), 79-91.	Intervention
King, A. C., Atienza, A., Castro, C., & Collins, R. (2002). Physiological and affective responses to family caregiving in the natural setting in wives versus daughters. International Journal Of Behavioral Medicine, 9(3), 176-194.	Includes other family carers other than spouse carers
Kirsi, T., Hervonen, A., & Jylhä, M. (2004). Always one step behind: husbands' narratives about taking care of their demented wives. Health (London, England: 1997), 8(2), 159-181.	Includes spouses in institutionalized care
Kolanowski, A. M., Fick, D., Waller, J. L., & Shea, D. (2004). Spouses of persons with dementia: Their healthcare problems, utilization, and costs.Research in Nursing and Health, 27(5), 296-306.	Quantitative methods and or design Biomedical or Psychosocial Focus
Kralik, D., Visentin, K., March, G., Anderson, B., Gilbert, A., & Boyce, M. (2008). Medication management for community-dwelling older people with dementia and	Review

chronic illness. Australian Journal of Primary Health, 14(1), 25-35.	
Kramer, B. J. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. The Gerontologist, 37(2), 239-249.	Quantitative methods and or design
Kramer, B. J. (2000). Husbands caring for wives with dementia: a longitudinal study of continuity and change. Health & Social Work, 25(2), 97-107.	Includes other family carers other than spouse carers
Laganá, L., Spellman, T., Wakefield, J., & Oliver, T. (2011). Ethnic Minority Status, Depression, and Cognitive Failures in Relation to Marital Adjustment in Ethnically Diverse Older Women. Clinical Gerontologist, 34(3), 173-189.	Quantitative methods and or design Biomedical or Psychosocial Focus
Lavretsky, H. (2012). The role of family caregivers and inappropriate medication use in the community-dwelling older adults with dementia. Aging Health, 8(5), 457-460.	Quantitative methods and or design
Leinonen, E., Korpisammal, L., Pulkkinen, L. M., & Pukuri, T. (2001). The comparison of burden between caregiving spouses of depressive and demented patients. International Journal Of Geriatric Psychiatry, 16(4), 387-393.	Biomedical or Psychosocial Focus
Lewis, M. L., Hepburn, K., Narayan, S., & Kirk, L. N. (2005). Relationship matters in dementia caregiving. American Journal Of Alzheimer's Disease And Other Dementias, 20(6), 341-347.	Intervention
Lieberman, A., Dziatolowski, M., Kupersmith, M., Serby, M., Goodgold, A., Korein, J., & Goldstein, M. (1979). Dementia in Parkinson Disease. Annals Of Neurology, 6(4), 355-359.	Biomedical or Psychosocial Focus
Lindgren, C. L., Burke, M. L., Hainsworth, M. A., & Eakes, G. G. (1992).Chronic sorrow: a lifespan concept. Scholarly Inquiry For Nursing Practice, 6(1), 27-40.	Includes other family carers other than spouse carers

References	**Exclusion Criteria**
Lindgren, C. L., Connelly, C. T., & Gaspar, H. L. (1999). Grief in spouse and children caregivers of dementia patients. Western Journal Of Nursing Research, 21(4), 521-537.	Includes other family carers other than spouse carers
Loboprabhu, S., Molinari, V., Arlinghaus, K., Barr, E., & Lomax, J. (2005). Spouses of patients with dementia: How do they stay together “till death do us part”? Journal of Gerontological Social Work, 44(3-4), 161-174.	Review
Madsen, R., & Birkelund, R. (2013). 'The path through the unknown': the experience of being a relative of a	Includes other family carers other

dementia-suffering spouse or parent. Journal Of Clinical Nursing, 22(21-22), 3024-3031.	than spouse carers
Majerovitz, S. D. (1995). Role of family adaptability in the psychological adjustment of spouse caregivers to patients with dementia. Psychology and Aging, 10(3), 447.	Biomedical or Psychosocial Focus
Malinowski, J. S. (1999). The thief called dementia. Journal Of Gerontological Nursing, 25(9), 53-54.	Not focussed on the Spouse Care Relationship
Massimo, L., Evans, L. K., & Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses. Geriatric Nursing (New York, N.Y.), 34(4), 302-306.	Includes spouse carers of partners who don't have dementia
McKenna, M. (2011). Two sides to the story. Journal of Dementia Care, 19(3),18-19.	Autobiographical
McParland, J., & Camic, P. M. (2016). How do lesbian and gay people experience dementia? Dementia (London, England).	Includes spouses in institutionalized care
Meiland, F. J. M., Kat, M. G., van Tilburg, W., Jonker, C., & Dröes, R.-M. (2005). The emotional impact of psychiatric symptoms in dementia on partner caregivers: do caregiver, patient, and situation characteristics make a difference? Alzheimer Disease And Associated Disorders, 19(4), 195-201.	Biomedical or Psychosocial Focus
Mendez, M. F. (2012). Loss of meaning for "marriage" in semantic dementia. The Journal Of Neuropsychiatry And Clinical Neurosciences, 24 (4), E56-E57.	Biomedical or Psychosocial Focus
Meyer, J., Mc Cullough, J., & Berggren, I. (2016). A phenomenological study of living with a partner affected with dementia. British Journal Of Community Nursing, 21(1), 24-30.	Includes spouses in institutionalized care
Miller, B., & Guo, S. (2000). Social support for spouse caregivers of persons with dementia. Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 55B(3), S163-172.	Quantitative methods and or design
Miller, J. B., DeWinstanley, P., & Carey, P. (1996). Memory for Conversation. Memory, 4(6), 615-631.	Not focused on Dementia and or Memory Problems and or Alzheimers
Monahan, D. J., & Hooker, K. (1995). Health of spouse caregivers of dementia patients: the role of personality and social support. Social Work, 40(3), 305-314.	Biomedical or Psychosocial Focus
Monin, J. K., Schulz, R., & Kershaw, T. S. (2013). Caregiving spouses' attachment orientations and the physical and psychological health of individuals with Alzheimer's disease. Aging and mental health, 17(4), 508-516.	Biomedical or Psychosocial Focus

Morris, L. W., Morris, R. G., & Britton, P. G. (1988). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. The British Journal Of Medical Psychology, 61 (Pt 3), 231-236.	Biomedical or Psychosocial Focus
Motenko, A. K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. The Gerontologist, 29(2), 166-172.	Biomedical or Psychosocial Focus
Mukadam, N. (2016). Stay with me. Lancet, 388 North American Edition (10063), 3085-3086.	Autobiographical
Mullan, J. T. (1992). The bereaved caregiver: a prospective study of changes in well-being. The Gerontologist, 32(5), 673-683.	Biomedical or Psychosocial Focus
Mullan, J. T. (1992). The bereaved caregiver: a prospective study of changes in well-being. The Gerontologist, 32(5), 673-683.	Biomedical or Psychosocial Focus
Murray, J. M., Manela, M. V., Shuttleworth, A., & Livingston, G. A. (1997). Caring for an older spouse with a psychiatric illness. Aging & Mental Health, 1(3), 256-260.	Biomedical or Psychosocial Focus
Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S. (2001). Subjective responses to caregiving for a spouse with dementia. *Journal Of Gerontological Nursing, 27*(3), 19-28.	Quantitative methods and or design
Neundorfer, M. M. (1991). Coping and health outcomes in spouse caregivers of persons with dementia. Nursing Research, 40(5), 260-265.	Biomedical or Psychosocial Focus
Nogueira, M. M. L., Neto, J. P. S., Sousa, M. F. B., Santos, R. L., Rosa, R. D. L., Belfort, T., Dourado, M. C. N. (2015). Spouse-caregivers' quality of life in Alzheimer's disease. International Psychogeriatrics / IPA, 27(5), 837-845.	Quantitative methods and or design
Nogueira, M. M. L., Sousa, M. F. B., Santos, R. L., Lacerda, I. B., Baptista, M. A. T., Dourado, M. C. N., & Neto, J. P. S. (2017). Perception of change insexual activity in Alzheimer's disease: views of people with dementia and their spouse-caregivers. International Psychogeriatrics, 29(2), 185-193.	Quantitative methods and or design
Litz, B. T., Zeiss, A. M., & Davies, H. D. (1990). Sexual concerns of male spouses of female Alzheimer's disease patients. The Gerontologist, 30(1), 113-116.	Formal Care Support form; the Formal Care Perspective
Nordtug, B., Krokstad, S., Sletvold, O., & Holen, A. (2013). Differences in social support of caregivers living with partners suffering from COPD or dementia. International Journal of Older People Nursing, 8(2), 93-103.	Quantitative methods and or design

References	Exclusion Criteria
O'Rourke, N., Claxton, A., Kupferschmidt, A. L., Smith, J. Z., & Beattie, B. L. (2011). Marital idealization as an enduring buffer to distress among spouses of persons with Alzheimer disease. Journal of social and personal relationships, 28(1), 117-133.	Focused on Research Methods
O'Rourke, N., & Wenaus, C. A. (1998). Marital aggrandizement as a mediator of burden among spouses of suspected dementia patients. Canadian Journal on Aging, 17(4), 384-400.	Biomedical or Psychosocial Focus
Pastor, D. K., & Vogel, B. (2011). Supporting community caregiving for a spouse with dementia: research with implications for practice. Home Healthcare Nurse, 29(7), 443-450.	Situated in institutionalized care (transfer to)
Peacock, S., Bayly, M., Gibson, K., Holtslander, L., Thompson, G., & O'Connell, M. (2016). The bereavement experience of spousal caregivers to persons with dementia: Reclaiming self. Dementia (London, England).	Includes spouses of whom the partner had passed away at the time of the interview. Not a spouse carer anymore.
Pearson, J. L., Teri, L., Wagner, A., Truax, P., & Logsdon, R. G. (1993). The relationship of problem behaviors in dementia patients to the depression and burden of caregiving spouses. American Journal of Alzheimer's Disease and Other Dementias, 8(1), 15-22.	Biomedical or Psychosocial Focus
Peeters, J. M., Van Beek, A. P. A., Meerveld, J. H. C., Spreeuwenberg, P. M. M., & Francke, A. L. (2010). Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. BMC Nursing, 9, 9p-9p.	Quantitative methods and or design
Peisah, C., Brodaty, H., & Bridger, M. (2008). Abuse by marriage: the exploitation of mentally ill older people. International Journal of Geriatric Psychiatry, 23(9), 883-888.	Not focused on Dementia and or Memory Problems and or Alzheimers
Perren, S., Schmid, R., Herrmann, S., & Wettstein, A. (2007). The impact of attachment on dementia-related problem behavior and spousal caregivers' well-being. Attachment & Human Development, 9(2), 163-178.	Quantitative methods and or design
Perry, J. (2002). Wives giving care to husbands with Alzheimer's disease: a process of interpretive caring. Research In Nursing & Health, 25(4), 307-316.	Includes spouses in institutionalized care
Pertl, M. M., Lawlor, B. A., Robertson, I. H., Walsh, C., & Brennan, S. (2015). Risk of Cognitive and Functional Impairment in Spouses of People With Dementia: Evidence From the Health and Retirement Study.	Biomedical or Psychosocial Focus

Journal Of Geriatric Psychiatry And Neurology, 28(4), 260-271.	
Peter-Wight, M., & Martin, M. (2011). When 2 is Better Than 1 + 1: Older Spouses' Individual and Dyadic Problem Solving. European Psychologist, 16(4), 288-294.	Not focused on Dementia and or Memory Problems and or Alzheimers
Pomara, N., Deptula, D., Galloway, M. P., LeWitt, P. A., & Stanley, M. (1989). CSF GABA in caregiver spouses of Alzheimer patients. The American Journal Of Psychiatry, 146(6), 787-788.	Biomedical or Psychosocial Focus
Poulin, M. J., Brown, S. L., Ubel, P. A., Smith, D. M., Jankovic, A., & Langa, K. M. (2010). Does a helping hand mean a heavy heart? Helping behaviour and well-being among spouse caregivers. Psychology And Aging, 25(1), 108-117.	Quantitative methods and or design
Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. International Psychogeriatrics / IPA, 28(4), 537-556.	Review
Pöysti, M. M., Laakkonen, M.-L., Strandberg, T., Savikko, N., Tilvis, R. S.,Eloniemi-Sulkava, U., & Pitkälä, K. H. (2012). Gender differences in dementia spousal caregiving. International Journal Of Alzheimer's Disease, 162960-162960.	Biomedical or Psychosocial Focus
Raivio, M., Eloniemi-Sulkava, U., Laakkonen, M. L., Saarenheimo, M., Pietilä, M., Tilvis, R., & Pitkälä, K. (2007). How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease? American Journal of Alzheimer's Disease & Other Dementias, 22 (5), 360-368.	Quantitative methods and or design
Raivio, M. M., Laakkonen, M.-L., & Pitkälä, K. H. (2011). Alzheimer's patients' spouses critiques of the support services. ISRN Nursing, 2011, 943059-943059.	Quantitative methods and or design
Raivio, M. M., Mäki-Petäjä-Leinonen, A. P., Laakkonen, M. L., Tilvis, R. S., & Pitkälä, K. H. (2008). The use of legal guardians and financial powers of attorney among home-dwellers with Alzheimer's disease living with their spousal caregivers. Journal Of Medical Ethics, 34(12), 882-886.	Quantitative methods and or design
Rev Temple-Jones, J. (2012). "I want to find my life again" dementia and grief. The Journal Of Pastoral Care & Counseling: JPCC, 66 (2), 5:1-7.	Situated in institutionalized care
Riley, G. A., Evans, L., & Oyebode, J. R. (2016). Relationship continuity and emotional well-being in spouses of people with dementia. Aging & Mental Health, 1-7.	Quantitative methods and or design
Roberto, K. A., Richter, J. M., Bottenberg, D. J., & Campbell, S. (1998).Communication patterns between caregivers and their spouses with Alzheimer's disease: a	Intervention

case study. Archives of Psychiatric Nursing, 12(4), 202-208.	
Robinson, K. M. (1990). Predictors of burden among wife caregivers. Scholarly Inquiry For Nursing Practice, 4(3), 189-203.	Quantitative methods and or design
Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. Aging & Mental Health, 9(4), 337-347.	Biomedical or Psychosocial Focus
Robinson, K. M., & Davis, S. J. (2013). Influence of cognitive decline on sexuality in individuals with dementia and their caregivers. *Journal Of Gerontological Nursing, 39*(11), 30-36.	Review

References	**Exclusion Criteria**
Rudd, M. G., Viney, L. L., & Preston, C. A. (1999). The grief experienced by spousal caregivers of dementia patients: the role of place of care of patient and gender of caregiver. International Journal Of Aging & Human Development, 48(3), 217-240.	Situated in institutionalized care
Samoilov, A., & Goldfried, M. R. (2000). The case of Katrina. Cognitive and Behavioral Practice, 7(4), 486-489.	Not focused on Dementia and or Memory Problems and or Alzheimers
Sanders, R. (2016). Dementia and marriage. Nursing Older People, 28(2), 13-13.	Review
Sanders, S., & Power, J. (2009). Roles, responsibilities, and relationships among older husbands caring for wives with progressive dementia and other chronic conditions. Health & Social Work, 34(1), 41-51.	Includes spouses in institutionalized care
Sarnoff, D. P., & Sarnoff, P. (2005). Assessing Interactive Creativity in Couples. The Family Journal, 13(1), 83-86.	Intervention
Sato-Dilorenzo, A., & Sharps, P. W. (2007). Dangerous intimate partner relationships and women's mental health and health behaviors. Issues in Mental Health Nursing, 28(8), 837-848.	Quantitative methods and or design
Savundranayagam, M. Y. (2014). Receiving while giving: The differential roles of receiving help and satisfaction with help on caregiver rewards among spouses and adult-children. International Journal of Geriatric Psychiatry, 29(1), 41-48.	Includes other family carers other than spouse carers
Schneider, J., Murray, J., Banerjee, S., & Mann, A. (1999). EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I Factors associated with carer burden. International Journal Of Geriatric Psychiatry, 14(8), 651-661.	Quantitative methods and or design

Searson, R., Hendry, A. M., Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. Aging and Mental Health, 12(2), 276-282.	Quantitative methods and or design
Shaji, K. S., Smitha, K., Praveen Lal, K., & Prince, M. J. (2003). Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 dementia research network. International Journal of Geriatric Psychiatry, 18(1), 1-6.	Situated outside of the 'Western World'
Shanks-McElroy, H. A., & Strobino, J. (2001). Male caregivers of spouses with Alzheimer's disease: risk factors and health status. American Journal of Alzheimer's Disease & Other Dementias, 16(3), 167-175.	Quantitative methods and or design
Sherman, C. W., & Boss, P. (2007). Spousal dementia caregiving in the context of late-life remarriage. Dementia, 6(2), 245-270.	Includes spouses in institutionalized care
Sharman, A. (2015). Subconscious thinking. The Safety & Health Practitioner, 33(5), 44-49.	Not focused on Dementia and or Memory Problems and or Alzheimers
Simonelli, C., Tripodi, F., Rossi, R., Fabrizi, A., Lembo, D., Cosmi, V., & Pierleoni, L. (2008). The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse. International Journal Of Clinical Practice, 62(1), 47-52.	Quantitative methods and or design
Simpson, C., & Carter, P. (2013). Mastery: a comparison of wife and daughter caregivers of a person with dementia. Journal Of Holistic Nursing: Official Journal Of The American Holistic Nurses' Association, 31(2), 113-120.	Quantitative methods and or design
Sistler, A. B., & Blanchard-Fields, F. (1993). Being in control: a note on differences between caregiving and noncaregiving spouses. The Journal Of Psychology, 127(5), 537-542.	Includes spouse carers of partners who don't have dementia
Skarupski, K. A., De Leon, C. F. M., McCann, J. J., Bienias, J. L., Wilson, R. S., & Evans, D. A. (2006). Is lower cognitive function in one spouse associated with depressive symptoms in the other spouse? Aging & Mental Health, 10(6), 621-630.	Biomedical or Psychosocial Focus
Small, J. A., & Perry, J. (2005). Do you remember? How caregivers question their spouses who have Alzheimer's disease and the impact on communication. Journal of Speech, Language, and Hearing Research, 48 (1), 125-136.	Intervention
Small, J. A., Perry, J., & Lewis, J. (2005). Perceptions of family caregivers' psychosocial behavior when communicating with spouses who have Alzheimer's disease. American Journal of Alzheimer's Disease & Other Dementias, 20(5), 281-289.	Includes spouse carers of partners who don't have dementia

Smith Barusch, A., & Spaid, W. M. (1996). Spouse caregivers and the caregiving experience: Does cognitive impairment make a difference? Journal of Gerontological Social Work, 25(3-4), 93-105.	includes spouse carers of partners who don't have dementia
Snow, K., Cheston, R., & Smart, C. (2015). Making sense of dementia: Exploring the use of the Markers of Assimilation of Problematic Experiences in Dementia scale to understand how couples process a diagnosis of dementia. Dementia.	Focussed on Diagnosis and Disclosure

References	**Exclusion Criteria**
Sparks, M. B., Farran, C. J., Donner, E., & Keane-Hagerty, E. (1998). Wives, husbands, and daughters of dementia patients: predictors of caregivers' mental and physical health. Scholarly Inquiry For Nursing Practice, 12(3), 221-234.	Biomedical or Psychosocial Focus Includes other family carers other than spouse carers
Spike, J. (2000). Narrative unity and the unraveling of personal identity: dialysis, dementia, stroke, and advance directives. The Journal Of Clinical Ethics, 11(4), 367-372.	Abstract and Article Non Accessible
Sternberg, S. A. (2004). Coping skills. Journal Of The American Geriatrics Society, 52(1), 162-162.	Autobiographical
Strawbridge, W. J., Wallhagen, M. I., & Shema, S. J. (2011). Spousal interrelations in self-reports of cognition in the context of marital problems. Gerontology, 57(2), 148-152.	Biomedical or Psychosocial Focus
Strawbridge, W. J., Wallhagen, M. I., Thai, J. N., & Shema, S. (2009). The influence of spouse lower cognitive function on partner health and wellbeing among community-dwelling older couples: Moderating roles of gender and marital problems. Aging and Mental Health, 13(4), 530-536.	Biomedical or Psychosocial Focus
Sussman, T. (2009). The influence of service factors on spousal caregivers' perceptions of community services. Journal Of Gerontological Social Work, 52(4), 406-422.	Quantitative methods and or design
Taylor, D. H., Jr., Ezell, M., Kuchibhatla, M., Østbye, T., & Clipp, E. C. (2008). Identifying trajectories of depressive symptoms for women caring for their husbands with dementia. Journal Of The American Geriatrics Society, 56(2), 322-327.	Quantitative methods and or design
Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A. R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with	Biomedical or Psychosocial Focus

stroke, dementia and Parkinson's disease. International Journal Of Geriatric Psychiatry, 17(1), 78-84.	
Thorpe, J. M., Thorpe, C. T., Kennelty, K. A., Gellad, W. F., & Schulz, R. (2012). The impact of family caregivers on potentially inappropriate medication use in noninstitutionalized older adults with dementia. American Journal of Geriatric Pharmacotherapy, 10(4), 230-241.	Quantitative methods and or design
Wawrziczny, E., Berna, G., Ducharme, F., Kergoat, M.-J., Pasquier, F., & Antoine, P. (2016). Modeling the Distress of Spousal Caregivers of People with Dementia. Journal Of Alzheimer's Disease: JAD, 55(2), 703-716.	Quantitative methods and or design
Willette-Murphy, K., Todero, C., & Yeaworth, R. (2006). Mental health and sleep of older wife caregivers for spouses with Alzheimer's disease and related disorders. Issues In Mental Health Nursing, 27(8), 837-852.	Quantitative methods and or design
Williams, C. L. (2011). What spouse caregivers know about communication in alzheimer's disease: development of the ad communication knowledge test. Issues in Mental Health Nursing, 32(1), 28-34.	Focused on Research Methods
Williamson, G. M., & Shaffer, D. R. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now. The Family Relationships in Late Life Project. Psychology And Aging, 16(2), 217-226.	Quantitative methods and or design
Wilz, G., & Fink-Heitz, M. (2008). Assisted vacations for men with dementia and their caregiving spouses: evaluation of health-related effects. The Gerontologist, 48(1), 115-120.	Quantitative methods and or design
Winslow, B. W., & Carter, P. (1999). Patterns of burden in wives who care for husbands with dementia. The Nursing Clinics Of North America, 34(2), 275-287.	Situated in an institutionalized setting
Wright, L. K. (1994). Alzheimer's disease afflicted spouses who remain at home: can human dialectics explain the findings? Social Science & Medicine, 38(8), 1037-1046.	Quantitative methods and or design
Wright, L. K., Hickey, J. V., Buckwalter, K. C., Hendrix, S. A., & Kelechi, T. (1999). Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. Journal of Advanced Nursing, 30(3), 552-563.	Includes spouse carers of partners who don’t have dementia
Wright, L. K. (1998). Affection and sexuality in the presence of Alzheimer's disease: a longitudinal study. Sexuality & Disability, 16(3), 167-179.	Quantitative methods and or design
Wright, L. K., Hickey, J. V., Buckwalter, K. C., Kelechi, T., & Hendrix, S. A. (1998). Spousal interactions in Alzheimer's disease and stroke caregiving: relationship to care recipients' functional abilities and physical and emotional health. Journal of the American Psychiatric Nurses Association, 4(6), 169-181.	Includes spouse carers of partners who don’t have dementia

Yoshioka, E., Yamamoto, S., Yasuda, M., Saijo, Y., & Kishi, R. (2013). Spouse caregivers and behavioral and psychological symptoms of dementia. Aging & Mental Health, 17(8), 966-972.	Situated in outside of the 'Western World'
Young, D., Rich, C. L., & Fowler, R. C. (1984). Double suicides: four modal cases. The Journal Of Clinical Psychiatry, 45(11), 470-472.	Not focused on Dementia and or Memory Problems and or Alzheimers
Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. The Gerontologist, 26(3), 260-266.	Situated in an institutionalized setting
Unknown Author. Couples with positive relationships describe better caregiving experiences. Nursing Standard,26(29), 15-15.	Review

1.3.1 Update systematic synthesis 24/07/2018

References	**Exclusion Criteria**
Hellström, Ingrid, and Sandra Torres. 2016. "The "not yet" horizon: Understandings of the future amongst couples living with dementia." *Dementia* 15 (6):1562-1585.	Includes other family carers other than spouse carers
Hernandez, Elise, Beth Spencer, Berit Ingersoll-Dayton, Alexandra Faber, and Allison Ewert. 2017. ""We are a team": Couple identity and memory loss." *Dementia*: 0(0) 1–15	Intervention
Riley, Gerard A, Laura Evans, and Jan R Oyebode. 2018. "Relationship continuity and emotional well-being in spouses of people with dementia." Aging & mental health 22 (3):299-305.	Quantitative methods and or design

Appendix 2 Ethics and Recruitment

2.1 Sections form the Ethics application/ protocol[31]

2.1.1 Potential Distress/Harm

Participants

This project won't produce any physical harm but its topic might upset the participants emotionally. Since health conditions and relationships are topics with a heavy emotional load. Informal interviews on aspects of these topics might upset the participants. I will give the participants the space to decide for themselves which information they want to share with me and which past experiences they want to reflect back on. By creating a high level of rapport participants should feel comfortable take that control. When they decide they want to share a story or experience and it upsets them and I find myself unable to comfort them I will tell them about services or support that they can contact like the local Alzheimer's Society or carer support groups.

Researcher

Fieldwork can also be emotional distressing for the researcher as I will spend a lot of time with the participants and will get to know them well and will develop empathy for their situation and stories. One way of controlling for emotional distress is the moderate level of participation that I am aiming for. In addition to this measure I will make sure that I have some time to retreat from the fieldwork and relax (Fontein 2014). I plan to only use five days a week to go to people's houses and keep two days a week to spend for myself.

When I would encounter serious issues during the project or feel emotional distressed I can rely on my supervisors, family members or close friends to give me either practical or emotional support. It would depend on the kind of issue or distress which person would be best to support me. If I would encounter some more serious emotional distress I know that I can access the free student counselling service of the university of Bradford to support me.

2.1.2 Confidentiality & Data Storage

Confidentiality

This study will work with the principle of anonymity. The participants will receive a pseudonym. Not only will I use a pseudonym in publications, I will also use this in my field notes. Since the university or Alzheimer's Society can ask for access to my data I find it important to protect the confidentiality of the participants in the raw data as well (DeWalt and DeWalt 2010). Since this project is funded by the Alzheimer's society and has one of the aims to improve the health care the results should benefit

[31] I only included these sections because they discuss topics that have not been discussed in detail in the ethics section of in the main body of the thesis.

the local healthcare landscape, I can't anonymize the location of the study. This means that people from West Yorkshire may still be able to identify participants, especially since the study will use thick description to produce its narrative. The thick description and use of visual methods make it easier to identify the participants. But the pseudonyms should at least prevent people who are not familiar with the local setting from identifying the participants.

Although the possible identification of research participants puts participants in a vulnerable position as the information they share with me will become accessible for other people in the community who might judge them on it or use it against them it also offers opportunities. When the participants are identifiable on a local level, local services may understand their situation better and could provide better support. I will try to safeguard for the possible negative consequences of the risk of breach of anonymity by judging whether the data I gather could potentially put the participant in a dangerous/harmful position. If I feel like the data might reveal things about the participants that could cause them serious harm or put them in a potentially dangerous position I will choose not to publish this information.

Since my study uses visual methods it is important to reflect a bit more extensive on the confidentiality. I will ask the participants permission to use the pictures from their photo diaries to publish, present or exhibit. I will leave them the option whether they would prefer that pictures which could potentially reveal their identity are being used or not and for which purposes, whether they agree to those pictures being published in academic circles or in wider circles. I will ask for written consent to use the pictures. Wills and colleagues (2016) discus in their visual study of domestic kitchen practices how even pictures of objects can reveal the identity of the participant and why it is useful to discuss this with the participants when asking for consent. I will treat the visual data according to the preference of the participant.In addition to that I will always consider whether the publication of certain pictures could be potentially harmful for the participant even when the participant gave consent to use the picture. It is well known that many participants don't always realize what the consequences of participating can be even when these consequences are communicated with them clearly. In the end it is always up to the researcher to safeguard the interests of the participants (DeWalt and DeWalt 2010).

Guided by these considerations I will follow Bartlett approach (2012) and inform participants that any picture of someone else they take during the photo diary period will not be used unless that person in the pictures gives consent for the use of the picture in the study.

Another important issue to raise is that as I work with different people from the same community at the same time and there is a chance that the participants know each other I need to be aware of the danger of gossip. As a researcher I find it very important to keep information about participants confidential even when they talk about the project together I will make sure that I refrain from giving participants information about each other. Breaching this rule could both put the rapport with the participants in danger and put them in a vulnerable position which could potentially harm them, for example when they don't live up to certain expectations in society

and are the subjected to social control (DeWalt and DeWalt 2010). This is especially important since this project is about couples and looks at them on both an individual and couple hood level. I have to safeguard that I don't share information that one of the couple has shared with me with the spouses on my own initiative.

Data Storage

All the data will securely be stored at the university. The consent forms and printed pictures and other material data like jot notes will be stored in a lockable draw, the digital data including possible recordings of conversations will be stored on a computer that is secured with a password log in.

2.1.3 Right to withdraw

The Participants can choose to withdraw from the whole study or just withdrawal their consent for the use of the photos at any point in the research project. Participants can withdraw from the project at any point in time and they don't have to give me a clarification why they withdrawal.

A high level of rapport is important in this study. I will build up a trust relationship with my participants. This way I hope to create an atmosphere in which the participants feel comfortable sharing their doubts about the project with me and feel able to tell me when they like to withdrawal from the study. As not everyone might be comfortable sharing that information with me face to face I will give them the opportunity to write me a postcard to let me know that they want to withdraw.

2.1.4 Safety

The research includes people with dementia and their caring spouse. People with dementia will sometimes develop behavioral problems. It is important to be aware of the symptoms of the health condition and the possible behavior issues and take these in consideration when making a decision about when to enter a house and whether it is possible to spend some time with only the person with dementia or only when the spouse is home. It should be noted that this research project takes place in the community with spouses who live in their own house. Usually when the home situation is dangerous and or the person with dementia has developed severe behavioral problems that person will be admitted to a nursing home. Also, when couples tell me they want to be part of the research project I will encourage them to reflect on their home situation and decide whether it is the right situation to invite a researcher into. When they don't feel comfortable with new people in their house and whether such a new situation would possibly trigger behavioral change that might be difficult to cope with.

When I as a researcher view a situation that concerns me because it is potentially dangerous, I will first discuss it with the couple themselves as they might not even be aware of the danger of the situation and they might be able to make some changes themselves to solve the issue. When the situation is so severe that they can't solve it themselves I will encourage them to search for help form outside,

like family members or services. If they resist the suggestion for help and the situation is so dangerous that it may put people at risk of severe injury I will inform authorities/services against their will, because it then constitutes ethical obligation to protect the participants. Before I would decide to inform authorities and or services I would first talk about my concerns with my supervisors and ask for their guidance in the situation.

Overall, I hope to control for unsafe situations and minimize any risks by drawing up on the expertise and experience of the experts by experience in my project to give me any advice when needed. This couple can give me some insight in how they would think about the project and what kind of home situations I could possible encounter and how to cope.

Lone worker policy

As my research project takes place outside of the university I will let my supervisors know, the address of the houses, and when I will conduct my project. They will get access to my research agenda so they will know where and when I am undertaking fieldwork. If we feel it would be necessarily I could inform my supervisors when I enter a house by sending a text and when I am leaving a house by sending another text.

When I am in a house and the situation is tense I can decide to leave the house and reflect whether coming back at another time would be better (Webster et al. 2014). For this project I will buy a separate phone which will always be on while I am conducting fieldwork. Not only will this improve the possibility of my supervisors to contact me, it will also come in handy to keep in touch with participants and at the same time preserve a bit of distance between me as the researcher and their personal life.

References

Bartlett, R. (2012) Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research* 22 (12), 1717-1726.

DeWalt, K. M. and DeWalt, B. R. (2010) *Participant observation: A guide for fieldworkers.* Rowman Altamira.

Fontein, J. (2014) Doing Research Fieldwork practicalities. In Konopinski, N. (editor) *Doing Anthropological Research A Practical Guide.* London: Routeledge. 70-89.

Webster, S., Lewis, J. and Brown, A. (2014) Ethical Considerations in Qualitative Research. In Ritchie, J., Lewis, J., Mcnaughton Nicholls, C., and Ormston, R. (editors) *Qualitative Research Practice: A Guide for Social Science Students*

& Researchers. Second edition. London: NatCen National Centre for Social Research/ Sage.

Wills, W., Dickinson, A. M., Meah, A. and Short, F. (2016) Reflections on the Use of Visual Methods in Qualitative Study of Domestic Kitchen Practices *Sociology* 50 (3), 14.

2.2 Consent Form

Consent Form

Understanding the quality of life for people living with dementia and co-morbidity living with their spouses in the community

Part A. General Study

I have read the information sheet and or have had it read to me.

YES/NO

☐ ☐

I understand what the project is about and why it is being undertaken.

YES/NO

☐ ☐

I have had an opportunity to ask questions about the research.

YES/NO

☐ ☐

I have been advised that it is my choice whether or not to take part in the research project (6 months).

YES/NO

☐ ☐

I agree with having regular house visits from the researcher over the duration of the project.

YES/NO

☐ ☐

I agree that the researcher can make observations, notes and tape recordings of some conversations during the project to use for the study.

YES/NO

☐ ☐

I agree that the researcher can use information that I have provided unless I ask the researcher not to use it.

YES/NO

☐ ☐

I am aware that I and my partner can withdraw from the study at any point in time during the six months of the research project.

YES/NO

☐ ☐

Part B. Photos

I agree to keep a photo diary for 28 consecutive days sometime during the six months duration of the research project.

YES/NO

☐ ☐

I give the researcher consent to use the photos I took for analysis.

YES/NO

☐ ☐

I give the researcher consent to publish the photos.

YES/NO

☐ ☐

I give the researcher consent to take pictures during the research project and use them for analysis.

YES/NO

☐ ☐

I give the researcher consent to publish the pictures she used during the research project.

YES/NO

☐ ☐

Name of Participant: **Signature:** **Date:**

Do you want to be kept informed of the findings of this study? Yes / No

Name of the researcher: **Signature:** **Date:** ☐ ☐

2.3 Example Flyer/Poster

UNIVERSITY of BRADFORD
School of Dementia Studies

Leading the fight against dementia
Alzheimer's Society

Understanding Daily Life Experience of Couples Living with Dementia alongside other Health Conditions in their own House

- **Do you or your partner live with dementia alongside another health condition?**
- **Do you live together in your own house?**
- **Would you like to share your daily life experience to help us understand the daily life experience of people in similar situations better?**

Please contact me so I can provide you with more information about my research project and how you can be involved. Your personal details and any information you provide will be handled with confidentiality.

Denise de Waal PhD Student

Phone: 01274236461 (work)

Email: d.dewaal@bradford.ac.uk

Mail address:
Faculty of Health Studies
University of Bradford
Richmond Road
Bradford
BD7 1DP

2.4 Information Leaflet

Information Sheet Denise de Waal 16/12/2016

Invitation to Participate in Research

Exploring the quality of life for people living with dementia and co-morbidity living with their spouse in the community

Couples' Daily Life Experience of living with Dementia and other Illnesses in their own Homes.

My name is Denise de Waal. I am a PhD researcher in Dementia care at the Alzheimer's' Society funded and supported Doctoral Training Centre on Transitions in Dementia care at Bradford University. My research focuses on how health conditions in combination with dementia influence couples' daily lives.

Who am I looking for? I am looking for couples where one of them lives with dementia and at least one other illness, and their partner is looking after them in their own home.

Why are you invited? The number of people diagnosed with dementia is still growing. It is well known that a lot of people keep living in the community after a diagnosis and are being cared for by a family carer, like their spouse. Many people who are being diagnosed with dementia already live with other health conditions. So far not much is known about living with both dementia and other illness of having to manage multiple problems at home. This study aims at gaining a better understanding of the daily life experience of couples in the community of whom one has developed dementia and other illnesses and the partner is the primary carer.

What are the Benefits of Participating in the study?

There are no financial or material benefits involved with participating in the study. There is the possible emotional benefit of having the opportunity to share your experiences.

What happens if you don't take part in the study?

There are no consequences involved with declining to take part. The decision not to take part in the study will have no cons

equences for the services that you use and the support you currently receive.

Withdrawing from the study?

You can decide to withdraw from the study at any point in time. The only thing you need to do is tell me that you would like to withdrawal either in person or by mail. You don't have to explain why, you can if you wish but it's not an obligation.

If you are interested in learning more about the project or if you have any specific questions about participating, please feel free to contact me at:

By Email: **d.dewaal@bradford.ac.uk**

By phone: **01274236461 (work)**

07802880908 (mobile phone)

Appendix 3 Data Collection

3.1 Interview Guide

Introduction

1. Thank the participant for being interviewed.
2. Introduce myself, my role and explain the purpose of the interview.
3. Introduce the topic of study and topics of the interview.
4. Explain the process of the interview, order of the topics and that it has an open flow. The participant can introduce topics, elaborate on a topic or ask to stop the interview, take a break or skip a topic.
5. Tell the participant that the interview will be audio taped.
6. Assure the participant of the anonymity of the data by the use of a pseudonym and the safe storage of the data at the university.
7. Ask for oral consent.

Consent:

Written consent will already been obtained at the start of the project. But before the interview I will ask again for oral consent. I will ask them for this consent after point 6 in the introduction.

Process:

1. Introduction
2. Switching on the audio recorder
3. Ask for some general information; name, address, name partner (when the person has dementia and some this information is difficult for them to tell me I will just move to the questions).
4. Start with the actual questions. Since this is a semi-structured interview I won't work with a pre-prepared interview question lists. I will follow a topic list and formulate the questions during the interview, the way they fit the flow of the interview. You will find the topic list at the end of the interview guide.

5. Give the participant the opportunity to raise a topic that hasn't been covert so far.
6. Ending the interview; thanking the participant for their time, turning off the tape recorder, asking if there are any additional questions or issues?
7. Remind them how they can contact me if they feel the need to do so.

Topic List:

- Identity (who are you? Did it change since the onset of the health conditions)
- Relationship (roles, responsibilities, emotions, connection with each other)
- Health conditions (which health conditions, how do they influence daily life)
- Health & Care support (Do you receive support, which support by whom, do you want additional support etc.)
- Home environment (Meaning of the house, function of different rooms, habits in the home, attachment to the house, medicalization of the house, changes in the house, private/public spaces etc.)

3.2 Photo Diary Guide

- Only Participants that have given their separate consent at the start of the project to be part of the photo diary will be included in this phase. (participants will always have to withdraw from this phase of the study if they like even if they have consent before)

Process:

1. Before the start of the Photo Dairy period I will assure them that the photos they take will be handled with confidentiality. And ask them for oral consent once again to be part of this phase of study.
2. Following their oral consent I will discuss with the participants which device they would prefer to take their pictures on. This can be a mobile phone, tablet, digital camera or disposable camera etc.

3. After the participant has chosen the device they prefer to use I will ask them if they any guidance or training using the device. If necessarily I will teach them how to use the device and provide them with information that they look at later like a small manual how to use the device to take a picture.
4. When they know how the device works I will give them a leaflet with some general guidance on what I expect them to do. To take one picture a day for 28 days of things that are part of their daily routine/experience and which they find important to share with me. And that it is important that both spouses keep their own diary, that they can help each other to take a picture when that is necessarily but that it's important that they keep their individual diary.
5. I will discuss with them whether they would like to have a prompt to help them remember to take a picture like a daily text/email or a calendar that tells them to take a picture.
6. Now they should be ready to start their photo diary. I will tell them that they can always contact me with any additional question about the photo dairy.
7. After the 28 days I will collect the pictures, by transferring them to my own digital device or collecting the film to be developed. I will make sure that the participant will get an own copy of the photo's they took.
8. When the pictures are developed and digitalized I will do some photo voice interviews with the participants to understand why they choice to take certain pictures.
9. If they have given their consent to publish the pictures they took, I will ask them whether there are certain pictures that they don't want me to publish.

On the next page you will find the Photo Diary guidance flyer that I will give to the participants.

3.3 Photo Diary Participant Guide

Photo Diary Participant Guide

How does it work?

You will take one picture every day for 28 days in a row (four weeks).

With which device should I take pictures?

You can take pictures with the device you prefer; you can discuss with the researcher which device would suite you best.

What should be in the picture?

The pictures should present your daily life experience and or daily routine. It is up to you to decide what you want to photograph as long as you think it says something about your daily life experience/routine. For example, a picture of your breakfast or other activities you do on a daily basis.

What if I don't like the picture I took and I decide to take another one?

If your device allows you to delete a picture and take a new one you can do so as long as you have one picture of every 28 days.

What if I have forgotten to take a picture?

Ideally it would be best to have a picture of every day but don't worry if you have forgotten to take a picture just skip that day and carry on the next day. It is not a problem if you don't have all 28 pictures at the end of the four weeks. It's not necessarily about the amount of pictures but about what the pictures can tell us.

What if I am worried I will forget to take pictures regularly?

You can ask the researcher for tools to help you to remember to take a picture. For example, a daily text message, a daily email or a calendar.

What if I am uncertain about the use of the device?

The researcher can provide you with an easy manual with steps how to use the device of your choice to take a picture. In addition to that she will be happy to teach you how to use the device and practice the use.

What happens with the pictures I take?

After the 28 days of the photo diary the researcher will collect the pictures and copy them to her own device. You will receive an own copy of the pictures that you can keep for yourself. The pictures will be handled according to your preference that you have indicated on the consent form. The pictures will either only be used for data analysis or also possibly be published in the future. The researcher will store the pictures safely at a device that is secured with a password log in. After the researcher has collected the pictures she will talk you through the pictures, if you have indicated that the pictures can be published on the consent form she will ask you if there are any pictures that you would not want to be published.

If you have any additional questions or queries feel free to contact the researcher.

Denise de Waal PhD Student

Phone: 01274236461 (work)

Email: d.dewaal@bradford.ac.uk

Mail address:
Faculty of Health Studies
University of Bradford
Richmond Road
Bradford
BD7 1DP

3.4 Life History Tool

Practical Guide Based on a life history guide developed by Dan P. McAdams, North Western University 1995.

To understand better how you experience your life and daily routine it would be helpful to know better who you are and what makes you who you are. This is an opportunity to tell your narrative. I would like to use the narrative to show that people who use services are much more than service users and how they experience services, health conditions and support might be influenced by who they are and how they have experienced life so far. This doesn't mean that I want to know everything. It is up to you to share with me what you think is important to know when I want to understand how you experience life. To do so I have created this practical guide that will take us through the story.

We can take our time to go through the story it doesn't have to be completed within one interview. The most important thing is that you feel happy and comfortable with what you share with me and we will do that in the pace that the story needs.

Feel free to ask me any questions about the process or tell me about any possible concerns. Also, if you don't want to tell me about a particular event feel free to tell me so.

Below you find the practical Guide.

Step 1.

You are telling me your story. This will be just a part of your life story you would like to share with me. Can you think about it as telling somebody your life as it is a novel? Can you split it up in different chapters around themes you find important to tell me?

Questions central to a story like that are:

- Who am I?
- How am I ?
- What do I like my story to tell someone?

Take some time to think about this and tell me briefly what 2 to 8 chapters you have in mind which persons play a role in it and which themes they include.

Step2. Experiences

A story is often build around Experiences/Events

Let us talk about 9 different experiences:

1. An experience that made you feel very happy, gave positive emotions
2. An experience that triggered negative emotions of for example sadness
3. A turning point? Is there an Event that proved to be a turning point, creating considerable changes in who you are or your life?
4. What is your earliest memory?
5. An important event from Childhood
6. An important event from Adolescence
7. An important event from Adulthood
8. An important event from after Retirement
9. One other important event.

Step 3. Looking back at the Chapters and Events

Which of the chapters/events proved to be the biggest challenge? How did you face the challenge? Were there people to support you? How do you think this challenge impacted on your life?

Step 4. Positive and Negative influence

- Can you give an example of a person/group of people or institution that has had a positive influence on your life?
- Can you give an example of a person/group of people or institution that has had a negative influence on your life?

Step 5. Interests, Hobbies, Story

- Can you tell me about your favourite media. A movie or tv show or music you particularity enjoy and how it influenced your life?
- Can you tell me about your favourite media: A novel or book or magazine you particularity enjoy and how it influenced your life ?

Growing up were there stories told in the family or by friends that you still remember, Can you tell me one story and why you remember it?

Step 6. From past to Future

- How do you like to imagine your future? What would be the most favourable scenario?
- What would be your last favourable scenario? Do you have any anxieties/concerns about the future?

Step 7. Personal Ideology

Now I would like to ask a few questions about your fundamental beliefs and values and about questions of meaning and spirituality in your life. Please give some thought to each of these questions.

1. Consider for a moment the religious or spiritual dimensions of your life. Please describe in a nutshell your religious beliefs or the ways in which you approach life in a spiritual sense.

2. Please describe how your religious or spiritual life, values, or beliefs have changed over time.

3. How do you approach political and social issues? Do you have a particular political point of view? Are there particular issues or causes about which you feel strongly? Describe them.

4. What is the most important value in human living? Explain.

5. What else can you tell me that would help me understand your most fundamental beliefs and values about life and the world, the spiritual dimensions of your life, or your philosophy of life?

Step 8. Central Theme

Looking back at everything we have talked about so far. Is there a central Theme or message you like to connect to the story?

Step 9. Other things

Are there any other things you would like to share with me to understand your life history better?

Appendix 4 Case Study

4.1 Case Study Framework Analysis Jane & Alan

M : Family Dynamics	N : Friends	O : Interaction with Others	P : Interaction with community	Q : Social Identity	R : Selfhood PWD
They are close to their daughter and her husband but don't mention their son often. He and his family live abroad and he works for the army. Their daughter and her husband live only a street away. They are close to the broader family, being godparents, visiting broader family regularly (Although the illness of Alan does prevent them from visiting family so often these days. This creates sadness). They both have brothers and sisters and Alan even had a twin brother but he died at birth. Recently Alan's sister died of dementia which	Friends still visit and bring Alan a book or the paper but their interaction with him has changed (Jane doesn't specify how). Friends are also a support network, a son of a friend is a plumber they will ask him to help with the bathroom. A friend to Jane to the job center when she was unemployed. Another friend took them to church. Another friend knit them a blanket. They have friends all over the country. Especially for Jane friends are very important. She already had lots of friends before they got married. (people are	The daughter came to visit her dad (they sang and clapped to music, description of Jane). The godchildren wanted a lot of attention of Alan when they came to visit. In the past Alan was also good with children. There was one foster child who didn't leave his side for years. Friends have changed they way they interact with Alan. (Jane doesn't want to specify how). They still visit friends at their house. Everyone in the community who walks by asks Alan and Jane how they are doing when they sit in the garden. Jane comments she would	They still interact with the community although they can't go to church so often anymore. Last time they went people in church didn't recognize him because he lost so much weight. They like to be part of the community Jane told me how much she enjoyed baking a cake for people at church. They are happy about the neighborhood they live in. Neighbors help each other, they put the bins outside for each other. Jane goes to Slimming world class with her neighbor. Neighbors sometimes recommend services	Alan: He used to take out the dog of his daughter for walks. He used to be asked to decorate peoples homes. His family (godchildren) like him a lot. Just like one of the foster children who didn't leave his side. And the boy from church/his friend looks at him as an expert on music.	

S : Alan Joking	T : Embodiment (2)	U : Emotions	V : Emotions Carer	W : Experiences Emotional	X : Frustration PWD
Jim likes to Joke about drinking. While he can't drink with his health conditions. "Shut up and drink your gin". "I don't like tea I rather have Guinness". About the way he met his wife: "She was in the pathway I tripped over her". "He was 29" "I was an old pensioner". He jokes about things he can't do: "Just run up the lawn and back again".	The physiotherapist told Alan that he was strong. Jane was surprised because he is so frail. She said that was probably because he used to do physical labor during his working life.	There is a sadness about their daughter and son in law not being able to have children. Jane is sad about the dementia and other illnesses of Alan but "united we stand".	The carer was shocked and surprised when the doctor told her he would put Alan on a palliative care pathway. She knew it didn't go well but not this bad. She finds dementia a sad illness. She finds it difficult to see a loved on in the hospital.	Alan's sister passing away was an emotional experience for them. One of their foster kids that had to go back to his mum after eight years with them. Caring for this foster kid in general was an emotional experience. Jane tells me that she once accidentally trapped Matthew's fingers between the car door and the boy didn't cry. The way that Matthew had been treated at home before he arrived at his foster parents really upset Alan and Jane.	Alan's frustration is mostly created by hospital admission. He talks about being frustrated with the ambulance services, with the discharge system of the hospital and with the hospital food.

AE : Challenges	AF : Foster Childeren	AG : Emotional Experience	AH : Past Experience Services	AI : Daily life Experience	AJ : Anxiety
Fostering children was challenging sometimes. There is only so much you can do for those children. One foster child was send back to his mum after eight years and went down the wrong path. He did ask for Alan and Jane after years, but as he was addicted to drugs the help that Alan and Jane provided him couldn't help him and they decided to cut of contact. The insecurity about how he is doing is difficult for them. Another challenge was the bakkery shop that they started which went bankrupt.	They have fostered multiple children when they were also bringing up their own family. This brought them joy of having a big family and taught them about people but also feelings of sadness as there is only so much you can do. Especially the story of Matthew and it brought them some guilt towards their own children. But their daughter told them that she thought they did the right thing, that the foster children learned them to share.	Matthew who had to go back to his parents after eight years made Jane and Alan sad and angry, especially Alan felt that Matthew's mum only wanted him home to babysit his brothers and sisters. First Matthews'little brother fell out of the window when he was babysitting and when he was 17 he ended up in youth prison. Around that time he contacted Alan and Jane again. They took him out for his 18th birthday and they stayed in touch. They send him some money to help but due to his drug addiction problems he was just using them for money	They have mixed past experiences with services. They have bad memories of social work as they decided that Matthew could go back to his mother although Alan had tried to warn them that it would not be a good idea to send him back to his mum. Alan recalls his lung operation 50 years ago. He talks about a matron on the ward that used to walk the ward every evening before bedtime and that you could always tell her if there was something. But you also had to be obedient. Jane recalls that her sister used to be a	They go to the ulcer clinic every week on Tuesday. They spend a lot of time at home. Jane tells about a moment when Alan catched a wasp in the kitchen. The television is usually playing loud because of Alan's hearing problems. Their daughter calls her mum everyday, sometimes upto an hour. Jane gets up does her prayers and then starts her caring tasks, she checks if Alan is up she gives him his medicines, makes him breakfast, she bathes him. Their morning routine takes quite a bit of time. In the meanwhile their	Alan has an anxiety to wet the bed at the hospital, he doesn't drink much because he is afraid that the nurse won't be there when he asks help to go to the toilet. Jane is concerned about the limited amount of food Alan eats. He is losing a lot of weight. There is anxiety in the family about Alan's health. Jane and Alan have an alarm at their house against people breaking into the house. Alan has an anxiety for flooding. Although they don't live close to a river. Alan is also a bit anxious about going to the clinic as he is

AQ : External Help	AR : Knowledge of Health Conditions	AS : Medicine Management	AT : Motivation to Care	AU : Danger caused by Health Conditions	AV : Experience having a health condition
They receive a lot of help from family. Their son in law and daughter look after Alan when Jane needs a break. And Jane's cousin comes and cleans the house. Jane says that she is happy that she and her family provide the care. She wouldn't want anyone in the house she is afraid it would make him feel anxious and uncomfortable. (She reasons that change is not good for people with dementia). Also she likes the fact that she takes care of him on her on, "one to one". Although Jane doesn't like too much external	Jane used be a volunteer in the hospital during that work she learned about dementia. She for example says that she wants to avoid change. And she recognizes confusion. She has got a general knowledge of health conditions, for example she comments that consitpation may make Alan feel unsettled. She also recognizes dehydration and the risks, she focusses a lot on getting Alan to eat and drink enough. Jane didn't have enough knowledge of the co-morbidities to know that Alan might be put on a palliative care pathway because	Medicine management is both in the hands of the carer,PWD and the health care professionals. A nurse comes to the house to give vitamine B7 injection. The Jane and Alan discuss when he will take his medicines. He takes Morphine on Tuesday for when his bandage gets replaced, when the pain is really bad he is allowed to take Morphine upto four times a day and she can call the GP anytime with questions about that. The doctor prescribed him some powder that helps to soften the	No explicit data	The fact that Alan doesn't like to drink creates a danger of dehydration. He doesn't eat much and lost his appetite this makes him more frail.	Alan seems frustrated with his health conditions, he had an incident in which he started screaming at Jane. Alan comments that his ulcers can come back anytime and that they are very painful. Alan comments that it is confusing to wake up in so many different places (when he has to go into hospital). He is frustrated that he doesn't feel like eating he does recognize that it is impossible but tells me that he can't.

A : Bourdieu Modus Operandi	B : Common Sense	C : Norms Values (2)	D : Opinion	E : Disposition Field	F : Cultural Capital
	<u>Shared norms, values and opinions:</u> Family friends and the community, people are important. Appreciate what you have if it is good don't think about changes you don't know what they will bring you. Treat people fair and honest, help people and you will receive a good deed in return. You should work to provide a living. Work in itself is important.(Both spouses worked till retirement). Children make their own decisions and their is not much you can do about it.	Family is very important to them. (they wanted a big family) They finding helping others important and they are happy to help. They also care about friends and the community. Jane: "People are important to me". They also believe that you shouldn't make unnecessary changes, "if it is not broken don't fix it". Jim talks about protecting his family, he likes to get a dog to do so. They appreciate what they have and believe that you shouldn't want anything else if	Alan rather uses a taxi than have a car: once you paid you are finished with the responsibility of it. Children make their own choices and you can't really do anything about that. People in society do their best to help each other but the people who shout the loudest usually get listened to more and get support. People who don't shout sometimes get neglected. Everyone should be heard and treated the same, fairness (Jane). Everybody is different and may not have had the same education (Alan)		Alan is Irish and Jane is English. (Irish symbols in the house on souvenirs,mugs etc.)He speaks Gaelic and uses sayings in this language but decided not to teach his children. The importance of family is symbolized in all the family pictures in the house. Jane likes to Knit, Alan likes to read autobiographies of working class people. Work is valued as important also by friends of them. Also the catholic religion is important. Interests are broad and different for both spouses.

G : cultural identity	H : Interests	I : Taste	J : Religion (2)	K : Economic Capital (2)	L : Social Capital
Jane is from Yorkshire. Alan is from Dublin, (irish symbols in the house, he talks about molly malone, he can speak Gaelic and he talks about Irish traditions as the pledge to not drink and Claddig ring)	Jane likes to knitt, she likes to bake and watch musicals. Alan like music, cd's records (mostly sixties music), reading autobiographies of working class people, comedians, crosswords. He also likes swimming. Alan also likes dogs, it's a returning topic, although he never owned a dog himself.	Alan likes poridge and fruit for breakfast and dislikes curry. The liked camping.	Religion is important to them. They are Catholic. They pray everyday. They are godparents of multiple children of their nieces and nephews. They have different symbols of their religion in their house, like a painting of Jesus on a hill in front of Jerusalem and a miniature statue of the pope. They are sad that they haven't been able to go to church so often anymore since Jim is ill. They used to go to mass daily. They tell me about their trip to the Vatican that was important to them. For Alan being Catholic is connected to being	They live in a small terraced house. Using taxis is considered expensive. Gluten free products are expensive, 3 pounds for a loaf. A car is considered to be expensive. He used to have a vauxhall, especially when he worked their it was cheaper because he could buy spare parts cheaper. When they buy something they announce the price (from 8 pounds reduced to 1.44). If things are not broken don't fix it. 45 pounds is considered a lot of money for a lock. They consider 500 pounds to be a lot of money. They used to go on	

Y : Personal identity	Z : PWD	AA : Awerness own health condition	AB : Social Identity Carer	Habitus (Norms and Values and Past Experi	AD : Past Experience (2)
Alan used to be a decorater. His ethos is simple, you better do something than sit there.	"I wasn't a pen pusher." He used to do decorating which he taught himself. He likes swimming.	He is aware of his health condition and refers to himself as a "jojo". When talking about his problems with eating he says it feels like food gets stuck in his throat and that it doesn't reach his belly. He didn't notice himself he had dementia, it just showed on a brain scan. Alan notices when it's cold in the house. He indicates he sometimes gets confused when he wakes up. He can identify which medicine he uses he would like a lower dose of. Also he complaints about having a Pneumonia	Jane is mostly the mum.		The dead of the sister of Alan. They had foster children for a long time in their life. It still makes them sad that they couldn't prevent Matthew from taking the wrong path. They have lived in the same house for 28 years. Alan remembers well the two dogs of a friend and both of them talk about a surprise party that Jane organized for Alan one time. Alan likes to talk about dogs. He also likes to talk about the fact that they haven't had any floods. Another experience is the baker they used to have. Jane being unemployed after the shop failed and she had to go to the job center to find a new job. Alan who took a job at the same place as jane after he retired. They talk about their daughter and son in law, when they lived in London and the dog they had. How they cared

AK : Caring practice spouse	AL : Assistive Tools	AM : Carer Frustration	AN : Carer Identity	AO : Changes Health	AP : Coping Strategies
Jane provides different kinds of care. She makes Alan food that could help him to gain some weight. She keeps an eye on his weight, for example she notice that close don't fit well anymore. She prepares the food in a way he doesn't have to chew to much, little pieces or uses the food processor. Caring is a tiring task. A lot of the care is focused on eating. Trying to encourage him to eat and drink, make him soup, make him the food he likes. She monitors his body closely and notices changes over the weeks. She tries to	In the hallway I notice a fold away wheelchair. They also have a alternating cushion (incubatie kussen). Alan can't sit without the cushion for longer than about 20 minutes. He also has a hearing aid. The hearing aid doesn't fit anymore so they put the volume of the television extra high. The have a headset for the television but it doesn't fit in the new tv therefore they have apologized to the neighbors for the high volume of the tv. They have appliances from social services to help Alan to take a bath and a chair in	Jane is frustrated with the gp not showing up when he said he would and not canceling the appointment. She is frustrated with health care staff as she feels like they could pay more attention to the person instead of only the health condition. She is frustrated with the fact that the carers had to leave their job and know only nurses work in health care institutions. She feels like the carers where more focused on the person. Nowadays she feels like some basic needs are not taken into account, like when she had to	Jane feels like she is always the carer. Even when Alan is in hospital she feel like she needs to remind the staff of things.	Jane closely monitors the changes in health in Alan one focus is on food. She keeps a close eye on his weight and his food and drink intake. She wonders how his appetite and taste can have changed so much, "he has been a very big meat person all his life". She compares his day to day fitness with earlier on. She also keeps an eye on his movement, for example she notices when he can't walk with his stick. She also keeps track of his dementia, for example she mentions how he keeps asking about people who have died years	They have different practical coping strategies to deal with Alan's changes in health: Their daughter bought him a small cup to make drinking easier. They can't go to the funeral of Alan's sister but send money to get a tree planted in the garden of her son where she always loved to sit. They bought headphones for the television so Alan could hear without having it on loud volume and disturbing the neighbors. Jane bought Alan a calender to help him remember the date. They also have multiple assistive tools like a booster

AW : Body	AX : Body Carer	AY : health condition carer	AZ : Body PWD	BA : co-morbidity	BB : Dementia & Co-morbidities
		Jane has got back problems, she receives physiotherapy. She has got coeliac disease for ten years. She needs to avoid glutten, she can eat them but then she knows that the next day she will need the toilet multiple times. She has got osteoporosis in her bones. Jane has to lose weight.		He is not very mobile anymore, has a wheelchair in the hallway. Lately he doesn't have the energy to walk with his stick. Sitting can be uncomfortable probably because of his low weight, Weight loss is a problem. The doctor couldn't find the cause of his loss in appetite, he will have a belly scan some time later. Alan gets tired easily, after 40 minutes of interviewing he is tired. He is got a hearing problem, he has got hearing aid. Alan has got dementia, diabetes since he was	When Alan went into the hospital for a heart problem they found out that he also got dementia. Because of the dementia he doesn't always recognize people and because of his hearing problem he can't always hear the doorbell. This caused an incident in which I was ringing the doorbell and waving at him but he still didn't open the door. Having the co-morbidities causes him to be in hospital more often. The stay in hospital creates confusion as it makes him go different places. The medicines for the

BC : Lost activities PWD	BD : Dementia (2)	BE : Being in the Moment	BF : Dementia and Truth	BG : Onset Dementia	BH : Pace of Living with Dementia
During his working life Alan used to decorates peoples houses. He can't go swimming anymore because of the ulcers. And because he doesn't have a lot of strength at the moment. Alan used to read books but because of the dementia he is now halfway through four books and the library wants them back .	The Dementia seemed stable till the summer, during a holiday in South Hampton Alan started to experience more symptoms. He confuses moments for example he seems to mix up his long operation of 50 years ago and a heart operation he had three years ago. "Dogs"is returning topic of conversations. Alan has difficulty differentiating between day and night. Also he keeps thinking that all the children still live in the house and he keeps asking about deceased	When we talk about their foster children Jim gets upset. He makes jokes.	He can't recall the storyline of the musical they watched the day before. He is convinced of the fact that the main characters all got divorced in the story. He thinks his daughter lived in Australia which she didn't. He says he took a pledge not to drink which he didn't.	It started with a heartproblem and when being confused in hospital they decided to do a brainscan and found the dementia. The summer was a turning point, during a holiday in southhampton Alan got more confused.	Everything goes slower. Breakfast, getting up in the morning. And activities can't be planned to long on beforehand.

BI : Future Plans	BJ : Gender	BK : General Changes	BL : Health Care & Services Experience	BM : Access to Health Care & Services	BN : Acces to Health Care
They still talk about future plans together. For example about making plans to make changes in the house. The "future plan"of moving into a granny flat with their daughter and son in law is not going to happen.	Jane doesn't have the confidence to take driving lessons again.	Since Christmas Alan lost a lot of weight and has problems swallowing food. Alan was put on a Palliative care pathway. Alan's health changes day by day. Alan's Sister has passed away.	Some health services visit them at home like the GP, nurses and the physiotherapist. For an appointment with the dietitian they have to take the bus or pay for a taxi (they find taxis expensive). Now the NHS doesn't provide gluten free food on prescription anymore it became quite expensive for Jane to get gluten free products. The wheelchair helps the ambulance services to get Jim into the ambulance.		Some health services visit them at home like the GP, nurses and the physiotherapist. For an appointment with the dietitian they have to take the bus or pay for a taxi (they find taxis expensive). Now the NHS doesn't provide gluten free food on prescription anymore it became quite expensive for Jane to get gluten free products. The wheelchair helps the ambulance services to get Jim into the ambulance.

BO : Contact with Health Professionals	BP : Experience of Health Care	BQ : Experience Services	BR : home environment	BS : Household tasks	BT : Relationship Couple
They were positive about the doctor that diagnosed the dementia. Their contact with their gp seems a bit different. For example he didn't call them to say he wouldn't visit. The physiotherapist also made a general comment about the strenght of Alan. The GP had been frank to Jane and said that Alan wouldn't die from dementia.	In general they feel like there is not enough attention for the "person" in health care. Examples are: bad communication in the hospital, delay of discharge. The hospital telling them that they couldn't bring their own blanket. Not enough attention for the patient. They didn't experience the "dementia friendly" ward as being "dementia friendly". Also health care professionals seem not always be aware of the co-morbidities of the patient. "Because they're not a commodity, they're a human being in that	She feels like care assistants can't provide the same care as familymembers. Care assistants don't have the time. She is happy about the services of Age UK as she feels like they are safe and trustworthy. It was recommended by a neighbor who works for them. Social services has provided them with assistive tools. They are part of a friends together group of the alzheimers society.	The live in a terraced house in a narrow street. In the living room are lots of small decorative things. Little souvenirs from Dublin, family pictures. The have a narrow hallway with a stairs and a small living room. Objects in the house remind of the health conditions like the special cushion Alan is sitting on. There is a statue of a Border Collie in their living room. He looks just like the dog their daughter used to have. The also have a lot of catholic symbolism in their house. A painting of Jesus overlooking Jerusalem,	Jane's Cousin helps with the household tasks, she comes to clean the house.Jane does the cooking and Alan sometimes helps with preparing the vegetables. Jane also does the washing. Her cousin also does the gardening and other things. Jane also comments that she never realized how much Alan exactly helped out in the household.	They met 49 years ago in a dancehall in bradford and have been married for 48 years. Jane once threw Alan a surprise party. They still think about changes in the house together. They decided together to become foster parents. They liked working together. Alan even spend three years after retirement working with Jane. Alan asked Jane to marry him just before she went on holiday to Italy. In the meanwhile he went to do a job at the Jane's parents house. When she came back from holiday she decided to say yes to his

BU : Dynamic between the couple	BV : Changes in Roles	BW : Moving On I and or We	BX : LOST ACTIVITIES TOGETHER	BY : Stand Together	BZ : Sustaining Couplehood
Jane mainly cares for Alan but he also still sometimes helps her out for example by catching a bee in the kitchen. Jane is clearly in a caring role over Alan keeping track of his health and fitness. Sometimes she finds it difficult to do the right thing for his health when he indicates he doesn't want to, she uses her power position as carer to make him do it anyway. Like when he wanted more morphine and Jane had to stay with the fact that he could only have that if he would eat more. Jane is very concerned about Alan and this	Before Alan got Ill they used to share all household tasks. Only now Jane realizes how much he actually did.	They seem to want to stay together be a team: Together we stand.	Since Alan can't drive anymore and Jane doesn't dare to learn to drive they have lost their ability to go places on their own. They also can't really travel anymore since Alan's health conditions are too severe. They can't go to church together very often anymore. They can only go if a friend comes to pick them up. They used to work together the last couple of years from their professional work life.	"But we get by" "We're doing that on Sunday, aren't we? He keeps forgetting but we like to do things as a team". Jane likes to remind Alan of them being a team. "United we stand".	Jane Actively likes to sustain couplehood by emphisizing what they could do together and arrange shared activities for them. She looks for conmformation of them being a team in the way she interacts with Alan.

CA : Activities Together	CB : Affection and Appreciation	CC : Commitment	CD : Lost Activities Caring Spouse	CE : Power	CF : Carer as Mediator
Jane arranges for them to go to family outings and makes sure that they have a lift or book a taxi. Or she invites people to their house. Or she thinks of activities they could do together in the house like watching a musical. And sometimes a friend suggests to pick them up for church.	"And then when Jim started to be ill, I never realized how much he did".	They never explicitly mention commitment but they talk about each other as a team who does things together.	Jane can't go to mass every day anymore.	Jane is in the power position. She cares for Jim and manages the health conditions. She also manages their relationship. She also likes to help Alan to interact with others in a way they would understand.	Jane seems to mediate Alan's contact between him and other around him.

CG : Experience of Keeping Photodiary	CH : Fieldwork Experience	CI : Interview Pwd	CJ : Turning Point
She told me that they still had the disposable camera's she suggested to send them by mail so it would save me a trip to their house. I said I could also pick them up whatever was more convenient for them. They dropped out of the photo diary study when Alan went on a palliative care pathway.	My personal experience in the field	Sometimes I don't know why I missunderstand him. If it is because I don't understand the joke or because he gives an answer that doesn't fit the question. Does he give that answer on purpose or does he have difficulty understanding me?	One turning point was when Alan lost his ability to drive a car. Another turning point was after Christmas when Alan started to have problems eating at drinking. The third turning point was when Alan was moved on to a palliative care pathway.

4.2 Example Case Study report: Jane & Alan

4.2.1Jane & Alan: Results Data Analysis

Introduction:

Jane and Alan have been married for 48 years. They have known each other 49 years. Jane is English and Alan is Irish. They met each other in a dance hall in the north of England. Both of them are in their seventies but Jane is a bit younger than Alan. They have always lived in the same area but moved house a couple of times. They have two children and used to foster children. Their house is a small detached house in a suburb of a big city. Some family lives locally and some live further away. They share their catholic believe.

Social Capital

Jane and Alan both have quite a lot of social capital, they have a big family, both brothers, sister, cousins, nephews, nieces and their own children. They also have a lot of friends living all around the country. They are active members of their church and talk to the people in their neighbourhood.

Family

Family is important to them, they are close with their daughter and son in law. They live close to their house and visit regularly. The daughter even calls her mum daily to talk about the day. In the past Alan used to walk their dog and he helped out decorating their house. Now they take care of him by helping out Jane with the caring. Their daughter goes with them to hospital appointments and she comes to sit with Alan when Jane needs a break. They even discussed the possibility of having a granny flat but decided that change wasn't a good for Alan. They don't have much contact with their son, he lives abroad with his wife.

They are also close to the extended family. They are godparents of the children of their nephews and nieces and they visit each other regularly.

Jane: "Um, it's just, um, we went to ….. for Christmas, didn't we, last year? Not …., my daughter and son-in-law went to ….., um, to see his parents. They hadn't been

for several years and, um, my niece in rang up and, Alan's her godfather, and asked us if we'd like to go to see them. This is their two, this is their two little girls, they're our little, Alan calls them his two liver birds . They're, um, nine and six now, and, er, we go, so we went for Christmas and had a lovely, um, Christmas Eve, didn't we?"

Alan: "Yeah".[32]

They are also close to some of their cousins. One second cousin of Jane helps them often. She comes to visit them once a week and does chores in their house. They are also close to some brothers and sisters, Jane's sister and her son lived with them for a couple of years when her marriage broke down.

Image1: Alan in their living room with two nieces.

Friends

Alan and Jane have a lot of friends all over the country. Jane always used
To have many friends:

Jane: "He said he'd never met anybody with as many friends as I had. But people are very important to me".

Jane co-ordinates the friendships. They have friendships in the family community and neighbourhood. They have friends from the church which they also like to help, like the boy from church who visits Alan and calls him his friend.

[32] The quotes in this report are raw fragments of transcriptions of interviews and conversations.

According to Jane since Alan has developed dementia friends still come to visit but interact differently with him. She doesn't specify how their interaction differs from before.

They also still try to visit family and friends but it has become more difficult because Alan can't drive anymore and his health prevents him from traveling long distances on public transport. Their friendships also serve as an informal support network. With friends they exchange information about solutions to problems and services they need. Like a friend's son in law who is a plumber.

Community

They are happy about the neighbourhood they live in. Neighbours help each other, they put the bins outside for each other. Jane goes to Slimming world class with her neighbour. Neighbours sometimes recommend services because they work there. They not only receive but also provide support for their neighbours, they raised money for a boy at church so he could go on a foreign field trip with school. They find it important to know their neighbours and take an interest in each other's lives, for example they can tell me whether the children of the neighbours are still in secondary school. Especially since there has been some criminal activity in their neighbourhood. When they sit outside in the garden neighbours often pass by and ask them how they are doing. Jane sometimes finds this annoying and likes to be able to read a book without being disturbed. This does show that they are active members of their community.

Interaction with others

According to Jane the interaction of people with Alan has changed but she can't specify it. The godchildren still ask a lot of attention of Alan. Alan has always been good with children, when they were fostering there was one boy who would never leave his side (fill in name).

When their daughter comes to the house to sit with her dad she likes to do activities with him that he likes. Like last week they listened to music, sang together and clapped. I will reflect on the interaction between Jane and Alan when I discuss their relationship.

People in the neighbourhood always ask Jane and Alan how they are doing. Due to Alan's illness the couple is not able to interact as much with the community

as they used to. Last time they were in church some people didn't recognize Alan anymore as he has lost so much weight since Christmas.

Cultural Capital

Alan and Jane are both Catholics. Alan is Irish and Jane is English. In the house there are multiple references to their catholic identity like a painting of Jesus. There are also multiple souvenirs from Ireland in the living room. They are a working-class family and find work important.

Religion

Religion is important to them. They are Catholic. They pray every day. They are godparents of multiple children of their nieces and nephews. They have different symbols of their religion in their house, like a painting of Jesus on a hill in front of Jerusalem and a miniature statue of the pope. They are sad that they haven't been able to go to church so often anymore since Jim is ill. They used to go to mass daily. They tell me about their trip to the Vatican that was important to them. For Alan being Catholic is connected to being Irish, he tells me about the Irish Claddig ring which also has religious symbolism.

Jane: *"Oh, yes, oh yes, very important, yeah. Before Alan was ill, we used to go to mass in the mornings, most mornings, and then last year I, Alan couldn't, was too tired or whatever. And then, um, it's just since, um, since Christmas really that I can't go everyday 'cause I can't leave him for too long. Um, but try and go, sort of, five or six days out of seven. Always on Sundays. Um, and then we have our, our daily prayers. And of course Lent started yesterday, Ash Wednesday, so that's a good season for us to improve your prayer life and deny yourself a few things. So we like that, don't we?"*

Alan: *"Yeah".*

Economic Capital

They live together in a small terraced house. Both of them have worked till the pension age. They don't have a lot to spend. They find many things expensive, taxis,

gluten free products, a new lock on the door etc. When they buy something, they announce the price (from 8 pounds reduced to 1.44).

Jane worked as an administrative assistant at a school, ran a bakery, worked in a kitchen. Alan worked in car factory, was a handyman, did decorating and worked in a kitchen as well.

Alan: "Oh, I used to go anywhere for, to earn a shilling, yeah, anywhere".

Interests

Jane likes to knit, she likes to bake and watch musicals.
Alan like music, cd's records (mostly sixties music), reading autobiographies of working class people, comedians, crosswords. He also likes swimming.
Alan also likes dogs, it's a returning topic, although he never owned a dog himself.

Common Sense

Norms and Values

People are important, friends, family, community. Treat people fair and honest, help people and you will receive a good deed in return. Having foster children taught them about people.
Children make their own decisions and there is not much you can do about it.

Appreciate what you have if it is good don't think about changes you don't know what they will bring you.

Jane: "But, er, we believe in if it works don't ..."

Denise "Mm-hm".

Jane "... don't fix it".

Denise "Yeah, yeah".

Jane "Or don't change it".

Alan "If it's not broken leave it alone".

Jane "Don't fix it, that's right".

You should work to provide a living. Work in itself is important.(Both spouses worked till retirement).
Moderation is a virtue:

Alan: "Just because you drink you don't have to drink every day".

Shared Habitus

Some of the shared experiences they have mentioned are the fact that they used to have foster children and that Jane's sister and their nephew have lived with them for a couple of years after her marriage broke down.

They also share experiences about holidays they went on together like their holiday to Vatican. They used to have a bakery which they had to close down in a year. They also share their experience of meeting each other in a dance hall.
They also like to talk about their daughter and son in law, they used to live in London and Alan redecorated their apartment. Alan likes to talk about the fact that he used to walk the dog of their daughter and son in law.

Individual Habitus Alan

Alan likes to talk about dogs. The dog of a former landlord many years ago, the two dogs of one of their friends and the dog of their daughter and son in law. He also talks about the house of an aunt that once flooded.
Alan also talks about the places where he used to go swimming like Dublin bay.

Individual Habitus Jane

Jane recalls the memory that she started a bakery which she had to close within a year. Being unemployed was an experience that made a big impression because she had never been unemployed before. She also talks about having a miscarriage when her mum died and how much she liked to have a big family.
She also recalls her memory of working as a volunteer for an organization supporting elderly and people with dementia.

Daily life experience

In this section I will discuss the daily routine, the home environment, the household tasks, general changes in daily life, anxieties of the couple, future plans and the

relationship of the couple.

Daily Routine

Their daily life is mostly situated at home. Managing health conditions is central to their daily life. Every Tuesday they go to the ulcer clinic to get care for Alan's ulcers on his legs. Not only do the health conditions create weekly appointments at the hospital they also influence the pace of day to day living and the activities that the couple undertakes. Sometimes the health conditions clash with other important parts of their daily life like their religion. They used to go to mass everyday but since Alan is so ill they can't go anymore. He can't go to church and Jane feels like she can't leave him at home on his own. They try to manage these different central themes by finding ways in which they can co-exists accepting the pace dictated by the health conditions, like described in the following quote:

Jane: "Okay. So, um, you were awake early this morning, weren't you? It was about ten past six and I said to him, it's too early to get up yet. So, um, he fell off to sleep again and I got up about twenty past eight. Um, I got in the bath and, er, washed my hair and everything, got ready, came down. Er, first thing I did was have a cup of coffee and then I did my morning prayers. Um, went up to see Alan about three times and he was still sleeping and finally he woke up at half past ten".

Another important theme in their daily life is family. Jane calls with her daughter everyday. They tell each other how their day has been. Family comes to visit regularly, and their cousin helps out with the household tasks. The also still like to visit family themselves and go to family gatherings although this has become difficult with Alan's health conditions.

The health conditions can always dictate daily life at any time. Last year with Christmas they decided to visit family in another city. While they were there Alan started to feel ill and went to hospital. He was diagnosed with pneumonia and had to stay in hospital for a couple of days.

The Home Environment

They live in a small terraced house in a narrow street. They are happy with their small house. They haven't changed big things in the house for the last 15 years. The

change of the kitchen around that time was the last major change they made. This reflects their attitude that if it is not broken, don't fix it. If you change things you don't know what the change will bring you. Their house also symbolizes other important themes in their live like family, religion and Alan's cultural background and his attachment to dogs. Their living room is filled with family portraits, symbols of Catholicism, Irish souvenirs and a statue of a dog like the one their daughter and son in law used to have. Image 1 shows some family portraits, a small statue of a married couple and some catholic symbols like the painting of Jesus.

The health conditions not only influence the daily routine but also influence the home environment. In some ways they enforce their own attitude that you shouldn't change things when not necessary:

Denise "Well first can you, um, I don't know, so you say change is not a good idea, and ..."

Jane "Because people with dementia".

Denise "Yeah, yeah, well do you keep that in mind now with your house as well, that you don't change any furniture and things like that?"

Jane "Yes".

Alan "Oh, yeah".

Jane "Yeah".

On the other hand are some changes non avoidable. They have already made small changes in the house informed by both their health conditions. Both of them have to sit on a special cushion. Jane because of her back problems and Alan because he lost so much weight that sitting can become painful. The special cushions and other assisting tools like a wheelchair in the hallway symbols the health conditions as part of daily life. Also the use of the house and it's interior changes based on the health conditions. For example Alan has to put the volume of the television very high because his hearing aid doesn't fit him anymore. I will elaborate further on these changes when I discuss the experience of living with health conditions.

Jane and Alan find it important that their house is safe. Recently there has been some criminal activity in the neighbourhood. They decided to get a new

lock on the door which makes them feel more safe. I will return to this topic when I discuss their anxieties.

Household tasks

Household tasks are often part of the daily routine. Some household tasks are carried out by their cousin who comes to clean the house and do the garden since Jane isn't able to do this anymore. Both Jane and Alan still do some small household tasks themselves. Jane likes to cook and puts a lot of effort in making meals that fit both their needs. She needs low fat food and Alan needs high fat food. These tasks usually blend in with the rhythm on the day and are undertake when they feel able to do so. Alan will help with small tasks like preparing vegetables.

Jane: "I was just pottering about put the washer on, etc, etc, the dryer and thinking about dinner tonight and one thing and another".

General Changes

Changes that are identified by the couple are the change in appetite of Alan after Christmas. He lost a lot of weight since Christmas. Alan's health changes day by day. Another turning point was when the GP put Alan on a palliative care pathway.

Another change was that Alan's sister recently passed away.

Another big change was the fact that Alan lost the ability to drive. Jane can't drive which means that they are less independent and mobile.

Anxieties

In the family there is a general concern about Alan's health because he has lost so much weight recently and has chest infections regularly. Alan shares some of these concerns as he says he is afraid to go into hospital as he might leave with a chest infection. And when he is in the hospital he has got an anxiety to wet the bed, when the nurses don't have time to help him quick enough.

Alan also has anxiety about the safety of the house, he is worried about floods (they don't live close to a river) and he is worried about people breaking into the house.

Future Plans

They still talk about future plans together. For example, they discuss how they might want to put two doors back into the living room next winter.

Alan: *"Yeah. I put them in the garage and then I got rid".*

Jane: *"They were in the garage and then we disposed of them but ..."*

Alan: *"It'd be handy to have them back on across there because sometimes in the winter you get a draft coming in through the kitchen".*

Jane: *"He feels very cold".*

Denise: *"Yeah".*

Husband: *"It's rather cold. It would make this a bit smaller and cosier".*

Denise: *"Yeah, yeah, I can imagine".*

Husband: *"Yeah".*

Wife: *"Well that's something to think about love".*

Husband: *"That's for next year now".*

Although they still talk about the future together, the health conditions do shape their future. They made plans with their daughter and son in law to both move houses and live together in a big house with a granny flat. After the diagnosis of dementia they decided to drop this future plan.

Relationship

"United we stand" is their spirit.

Image2 Jane and Alan (Portrait taken as part of their photo diary)

They have been married for 48 years and Alan comments that they only need two more years to get an “egg”. They trusted each other and used to respect each other’s choices. Like when Jane came home with a new foster child Alan would just agree it and not be angry because she didn’t discuss it upfront. They shared certain ideas and norms and values. It is like what the other does, I do. Alan also supported Jane when she wanted to start a bakery.

They like to hold on to doing things together and deciding together. For example, when they explain how they like to face the challenge of Alan’s drop-in appetite:

Jane: *Small amounts. So we’re getting there, aren’t we, love?”*

Alan: *“Yeah. We’re okay”.*

Although they like to hold on to doing together and making decisions together there is a shift in power balance from more equally to a more powerful position for Jane as carer.

Jane: *“Well, we used to, when Alan first started to be ill, we used to share everything, didn’t we?”*

Alan: *“Yeah”.*

Jane: *"And then when Alan started to be ill, I never realized how much he did".*

Jane is clearly in a caring role over Alan keeping track of his health and fitness. Sometimes she finds it difficult to do the right thing for his health when he indicates he doesn't want to, she uses her power position as carer to make him do it anyway. Like when he wanted more morphine and Jane had to stay with the fact that he could only have that if he would eat more.

Jane is very concerned about Alan and this caring role. Alan sometimes has difficulty accepting the health conditions, in combination with the roles of carer and cared for and its power balance it creates conflict. This shows in the following fragment from my field notes:

Then at night she tried to convince him to eat half a scone. She had to tell him that she couldn't give him anymore morphine if he wouldn't eat something. So, he eventually agreed and ate half a scone and she had the other half. She tells me that she feels like she has tried so many things to get him eating. She makes him the food he likes, she tried making small portions so he can have small portions multiple times a day but he wouldn't have them. Also, two days ago a niece with her children visited and the children made lemon curt, she hoped that Alan would eat it because the children made it for him. But he didn't. He said he couldn't.

Being the carer also puts Jane in a role of mediator. She is the one who has to comment on Alan's health and fitness to both care providers and friends and family. For example, she tells me that she won't call her daughter when she is on holiday as her daughter will expect it must be bad news about her dad.

Jane actively tries to counter this change in power balance created through change in roles by holding on to activities they can still do together.

Shared activities

Jane likes to remind Alan of them being a team. She likes to emphasis that they still do activities together and as part of their photo dairy they included a portrait of them together (image 2).

Jane: "But we get by". "We're doing that on Sunday, aren't we? He keeps forgetting but we like to do things as a team". "United we stand".

Jane arranges for them to go to family outings and makes sure that they have a lift or book a taxi. Or she invites people to their house. Or she thinks of activities they could do together in the house like watching a musical. And sometimes a friend suggests to pick them up for church.

Jane actively tries to remind Alan of the activities they do together, although he can't recall them. Like about a Sunday afternoon when they watched three musicals together:

Jane: "Can you remember what we did on Sunday afternoon which we've never done before?"

Alan: "What?"

Jane: "When we, you said to me that there was, um, um..."

Alan: "Sunday afternoon?"

Jane: "Yeah. And there was, I don't know what TV channel it was and there was, with it being the Oscars, it was the musicals, a 24-hour showing of different musicals".

Alan: "Ah, yeah".

Jane: "What did we watch?"

Alan: "I don't know".

Jane: "Good. Yeah, um, I can't remember the last one meself now. We watched three. And we sat here for over six hours having a drink, you know, coffee or whatever it was, and we just really enjoyed it, didn't we? 'Cause it was a, such a miserable, cold, freezing day and, um, we'd had some, my daughter and son-in-law had had some friends up from Southampton and they came to see us in the morning and went off back on the journey down there. So it was, we just decided to do that. We've never sat and watched three films, have we?"

Alan: *"No".*

Jane: *"We just had some, a little bit of fruit and everything and we just enjoyed it".*

Lost Activities together

They still do activities together but they have also lost the ability to do certain activities together. Important activities they can't do as often anymore are visiting their friends and family all over the country and going to mass together. They speak about these activities in past tense.

Alan: *"So I was always, always busy in a way".*

Wife: *"We were always doing things, always, 'cause we've got friends all over, up and down the country.*

They always used to share a lot of activities. They even worked together at the same workplace during the last three years before retirement.

Commitment and Affection

They don't mention their motivation to be with each other explicitly but you can tell they are committed to being together by the effort Jane puts in to being a team and the remarks both of them make about decisions they made in the past.
Also, there is Alan's comment about needing two more years of marriage to get a golden egg.

Affection is also not something they show explicitly or mention a lot. It's almost as if they don't question commitment and affection. Jane only once shows affection and appreciation explicitly when she comments on never having realized how much Alan did in the house till he got ill.

The affection and commitment show in comments they make like the following comment of Jane:

Jane: "But we get by" "We're doing that on Sunday, aren't we? He keeps forgetting but we like to do things as a team".

Jane: "United we stand".

Experience Health and Illness

Coping Strategies

Different coping strategies to cope with different aspects of their daily living can be identified in the case of Jane and Alan. First of all there are the coping strategies to deal with the health conditions of both spouses. These are numerous including the caring practice itself, assisting tools, and the external help for the caring. I will elaborate on these topics in other paragraphs.

There are also the coping strategies to cope with the social and identity aspects of living with dementia and other health conditions. How they cope with sustaining their relationship was discussed in the section on relationship. How they cope with possible changes to their identity will both be discussed in the section on caring and the section on identity later on in the rapport.

Caring Practice

Jane provides different kinds of care; personal care, preparing food, monitoring Alan's health, medicine management and keeping track of all their medical appointments. Jane's attitude to caring is: It's tough but you accept it. Catherine sometimes helps out by watching Alan when Jane needs to go somewhere. She told her mum that Alan is not anxious once he knows she is on her way back. Which indicates that Jane is the main carer and he likes to have her around.

Monitoring Alan's health is one of the main tasks of caring and is interconnected to the practical activity of caring. Jane keeps track of his weight by paying attention to the fit of his clothes and the amount of food he eats. To try to stabilize his weight she tries to make him fat food that is easy to chew and which he likes to eat. He seems to have developed problems with chewing food. Paying attention to his nutrition is a big part of the caring role. She tries to encourage him to eat and drink every day.

Monitoring Alan's health is also important to recognizes changes in the health of Alan. It enabled her to recognize the symptoms of dementia early.

Changes in Health

Keeping an eye on Alan's weight and appetite helps her to monitor bodily processes in general and gives her a benchmark to compare the current fitness of his body with his fitness before:

Jane: "he has been a very big meat person all his life".

She compares his day to day fitness with earlier on. She also keeps an eye on his movement, for example she notices when he can't walk with his stick. She also keeps track of his dementia, for example she mentions how he keeps asking about people who have died years ago. She also monitors how much he sleeps during the day. On top of this she keeps track of all his health conditions including new infections, for example she mentions how his cellulitis has cleared up she measures his sugar levels (diabetes). Basically, she monitors his bodily functioning. For example, she monitors his bowel movement. Also, she keeps an eye on whether he is warm or cold.

Not only does she monitor his health and body by keeping track of his weight and eating habits, she also monitors his physical movement, for example she keeps track of whether Alan does his physiotherapy exercises.

Although she tries to monitor the bodily functioning of Alan closely she doesn't always pick up on all health changes. Jane didn't notice that Alan had an enlarged prostate. She commented:

Jane: "you are not going to watch your husband every time he goes to the toilet".

The health care professionals in the hospital noticed his enlarged prostate.

Alan also identifies changes in his health himself I will explain this further when I discuss his experience of living with a health condition. Monitoring changes in health are a shared task between the caring spouse, person living with the health condition and the health care professional.

Knowledge of Health Conditions

Jane used to work as a volunteer in a hospital which helped her to recognize health conditions and monitor them, for example she recognized Alan's symptoms of

dementia early. (I will further elaborate on this monitoring practice in the section on changes in health). She also has got a general knowledge of the functioning of the body and some common conditions that could influence the wellbeing of somebody like constipation and dehydration.

She can recall the names of all the health conditions of Alan and herself and has some ideas about aspects that she should pay a lot of attention to like the nutrition for them both, the medicine management and avoiding change to avoid unnecessarily confusion in Alan.

Although she has adopted some strategies of monitoring which she learned about as a volunteer in the hospital she hasn't had a professional training in caring and doesn't have an elaborative knowledge on Alan's health conditions and how they might co-influence each other. Over the last couple of months Alan had lost a lot of weight and the intake of food, fluids and medicines had become a struggle. Although Jane recognized this was very concerning and she tried to combat it with paying extra attention to these aspects she didn't connect this weak state of Alan's body to the influence of the co-morbidities on the body. How both reinforced the weak state of his body. When Alan developed a new chest infection and the GP told them that Alan wouldn't die of the dementia but from one of the co-morbidities or an extra infection like the chest infection Jane seemed surprised to hear this.

She could equally have been surprised because she actively resisted to think about Alan's health in this manor or because she just didn't make this connection.

Medicine Management

Medicine management seems to be a shared task between Jane, Alan and health care professionals. Both Jane and Alan have some knowledge about the medicines they have to take but Alan sometimes confuses which medicines he takes for which health condition. Like in the following example, he knows he takes warfarin and that this medicine has changed but he thinks he takes it for his diabetes while he actually takes it for his heart condition.

Alan: *"Well, I used to be on warfarin for my diabetic, and they changed it and they put me on a [small tablet 0:01:11] which is much better. I don't have to go as often for a check-up, so that's good".*

Denise: *"Yeah".*

Although they both have a knowledge of the medicine they take Jane seems to have the role of managing the medicines and its intake. She does try to include Alan in this task as shown in the following quote:

Jane: *"And then he had, um, he had his, um, first thing he had was his drink for his, um, his vitamins, the drink which he hates so we decided to get that over with in the morning if we can and then it's done. And then for breakfast he had, um, porridge and blueberries, didn't you, and a cup of tea and all his tablets".*

Jane has a general knowledge of how to manage the medicines and which medicines treat which condition. She does get support from health care professionals to manage the medicines. There is a district nurse who comes to their house to give Alan his B7 injections and she can contact the GP about medicine use till 6.30pm everyday for example when it comes to managing the morphine intake of Alan. After 6.30pm she needs to call the emergency number.

Apart from the medicines he needs to take every day because of the chronic illnesses Alan also needs to take other medicines ones in a while. He needs to take powder that helps to clear up his constipation and antibiotics to treat the chest infections he gets regularly. Besides the monitoring of the health conditions and bodily processes there is also a more practical side to caring. Assisting tools can help with this part of caring.

Assisting tools

Jane and Alan have multiple assisting tools to enable them to continue their daily routine. The health conditions can make certain parts of the daily routine more difficult, the tools help to cope with such difficulty. Sometimes these are tools provided by support services and health care services like the alternating cushion, the booster seat for the bathtub, the chair in the shower, the wheelchair Alan's hearing aid and the special cushion for Jane's back.

Alan needs the alternating cushion to be able to sit for longer than 20 minutes. Without the cushion it becomes painful after 20 minutes. On top of that he does spend most of his day sitting in his chair as he also not very mobile anymore.

He gets easily tired. The loss of mobility is coped with by providing them with a wheelchair.

The booster seat for the bathtub is used to keep his ulcers dry when he takes a bath. When he sits on the seat he can put his legs outside of the bathtub to keep them dry. The chair in the shower is provided so he doesn't have to stand all the time when he wants to have a shower.

Sometimes it are objects that people have changed into tools themselves like the garbage bag that they put over the bandage on Alan's legs to keep them dry while taking a bath or the headset they bought to connect to television so Alan can watch television while his hearing aid is being fixed by putting up the volume without disturbing the neighbours.

There is also the small cup their daughter both him to encourage him to drink more and the calendar Jane bought at the supermarket to help Alan to remember what date it is.

These tools sometimes enable people to cope with difficulties in their daily routine effectively like the alternating cushion and the booster seat for the bathtub. In other cases the tools are not adequate to cope with the challenges effectively. This could be because the tools are not adaptable to their daily life situation, like the headset that Alan and Jane bought who didn't connect with their television. But they could also become inadequate along the way like Alan's hearing aid that doesn't fit anymore because he has lost so much weight over the last couple of months. Other assisting tools could be more effective when used more regularly and more different situations like the wheelchair which barley is used. Jane and Alan comment that the emergency services use it to help Alan into the ambulance when he needs to be admitted to hospital.

External Help

Besides assisting tools external help could serve as a coping strategy. Alan and Jane receive most external help from their family. Their son in law and daughter look after Alan when Jane needs a break and Jane's cousin comes every week to help out with the household tasks like cleaning the house and working in the garden.

Jane says that she is happy that she and her family provide the care. She wouldn't want anyone else in the house she is afraid it would make Alan feel anxious

and uncomfortable. (She reasons that change is not good for people with dementia). Also, she likes the fact that she takes care of him on her own, “one to one”.

Although Jane doesn’t like too much external help they do receive quite a lot of health care in the home. Health and services visit them at home; district nurses, the GP, and the physiotherapist. When Alan went on a palliative care pathway they had to accept even more external help from health care professionals as nurses and the GP visited more regularly.

Motivation to Care

Jane doesn’t specify her exact motivation to care. It seems to be something she doesn’t question but just does. Her commitment to her marriage and attitude of being a team with her husband might be motivators to care.

Carer Frustration

Most of the frustration Jane feels as a carer are about how the health care professionals carry out their job. She is annoyed about the fact that the GP sometimes doesn’t keep to appointments and even forgets to cancel. This leaves Jane and Alan wait for nothing. She is also disappointed about the care that Alan receives in the hospital. She feels like they should enable staff to have more time for their patients paying attention to who they are and not only their health condition. She also thinks that they don’t always seem to take into consideration the co-morbidities of Alan. Although she is frustrated with the way the professional health care providers carry out their job she also acknowledges that they try their best and are doing a difficult job.

Jane: *“And then one nurse goes off and the new nurse comes on and she doesn't know he’s a new admission, but yet she should do. Oh I didn’t know he’d only just come in, I didn’t know you hadn’t… And we’d, we’d been in casualty for six hours. Do you know, it’s…”*

Denise: *“Oh, yeah”.*

Jane: *“… it’s hard, it’s very hard. Um I know they do their best, and my sister’s a nurse and my niece is a nurse…”*

Denise: *"Yeah".*

Jane: *"… but it's, it's very, very difficult".*

She is also a bit frustrated with the difficulty of her own caring job. All the co-morbidities of Alan and all the medication sometimes make it hard to manage all the health conditions at the same time.

Experience Having Health Conditions

Alan: In general Alan seems to be frustrated with his health conditions. He is aware of them (as illustrated by the fragment below) and comments that they cause him discomfort like his loss of appetite and the pain of the ulcers which can come back anytime. He also seems to be frustrated about all the hospital visits he needs to make because of the co-morbidities. He comments that it is confusing having to wake up in different places.

Jane: *"At the hospital they wash him ..."*

Denise: *"They do it within ..."*

Jane: *"... every time. So they put, um ..."*

Denise: *"... the hospital, yeah".*

Alan: *"So it gets a good wash".*

Jane: *"... InfaCare, which is, um, for babies ..."*

Alan: *"Yes, it was good yes..."*

Jane: *"... because he has such sensitive skin".*

Denise: *"Yeah".*

Jane: *"And it was done yesterday, wasn't it?"*

Alan: *"Yeah. What they had to be sure of, um, when they did take the bandage off there was no blood ..."*

Denise: *"Mm-hm".*

Jane: *"Sticking".*

Alan: *"... in".*

Jane: *"Yeah".*

Alan: *"So it's been good for the last two weeks".*

Jane: *"It's been dry, has the leg".*

Alan: *"Dry".*

Jane: *"Very bad eczema on it but it's dry".*

Denise: *"Okay".*

Jane: *"So we're just hoping that another won't suddenly break out".*

Alan: *"But there's no guarantee that, about the varicose vein ulcers coming back, they could come back without anyone".*

Denise: *"Yeah, you don't know?"*

Alan: *"No".*

Denise: *"Mm".*

Alan: *"No. The last time was about two weeks and I had to go back up to the hospital and get that put on the computer for me, for dressings".*

Denise: *"Is it painful?"*

Jane: *"Oh yeah. Terrible painful. Denise is asking is it painful".*

Alan: *"Not now. A couple of months ago it started to get better but I still have to keep going to have them dressed. You can't leave them undressed... When I was in hospital a couple of weeks ago they took, they took, they took the bandage off once and because they don't put honey that goes on there, they put dressing, so they just put a dressing until I got back to my own hospital".*

Health conditions Jane

Jane has got back problems, coeliac disease, osteoporosis and is overweight.
She receives physiotherapy for her back problems. She has had coeliac disease for ten years and needs to follow a gluten free diet.

Health Conditions Alan

Co-morbidities

Alan has got multiple health conditions, diabetes, dementia, COPD, heart problems, cellulitis in his knees, ulcers on his legs, bad eczema, a hearing problem and mobility problems. He also has additional health problems like a persisting weight loss which is caused by a drop in appetite and a suspected difficulty to chew. The danger of getting dehydrated, constipation and a vitamin deficiency. In addition to this he gets chest infections regularly and is often tired.

Dementia

The symptom of dementia that Alan experiences most is confusion. He started to be confused more often after their holiday in Southampton last summer. This confusion shows in different ways. Sometimes he can't differentiate between day and night. He also has moments in which he thinks that their children still live with them or that he asks about deceased family members.

In the morning when he gets up he doesn't know what day it is. Last week he even asked Jane*: Who lives here?*

Jane describes Alan's dementia as following:

"You know, 'cause Alan has good days and bad days and is somebody's who's very confused".

Alan also has clear memory problems. For example he can't recall what he did the day before.

Onset Dementia

Jane recognized the symptoms of dementia early. Three years ago, when Alan went

into hospital for a heart operation he became confused. Jane told the hospital staff that she suspected dementia and they decided to do a brain scan. Alan was diagnosed with dementia early on.

Being in the Moment

As Jane already mentioned in her description of dementia, dementia is linked to temporarily. It can change day by day, moment by moment. Because of this temporarily character living with dementia is a lot about living in the moment. The emotions that someone shows in the moment.

Dementia and Truth

Not only does dementia cause problems to recall memories, sometimes memories become mixed up or memories are filled in with fiction. When Jane talks to Alan about the musical they watched together the other day he comments that all couples got divorced which didn't happen in the musical. He also at some point says that he took a pledge at the church not to drink, which he actually didn't.

Pace of Living with Dementia

Not only does temporality play a role in living with dementia, the whole pace of daily living changes. Everything goes slower; breakfast, getting up in the morning. And activities can't be planned too long on beforehand.

Co-morbidities and Dementia

They diagnosed him with dementia after he went into hospital for a heart operation. The stay in hospital made him confused and he was diagnosed with dementia. Because of all his co-morbidities he regularly ends up in hospital. The stay in hospital causes confusion every time. We could even question whether the confusion is always caused by the dementia. He also has had multiple chest infections, when the body is weak and tries to fight of an infection it might also cause confusion.

The dementia and co-morbidities also create other difficulties. This showed one afternoon when I came to visit Jane and Alan. I rang the doorbell and waved at him but he didn't open the door. He said he didn't recognize me and hadn't heard the doorbell.

Lost Activities Alan

The dementia and co-morbidities have made it impossible for Alan to do certain activities he always liked to do like decorating, swimming and reading. He says he still reads books but actually he has got four books of the library in which he never got further than halfway. The loss of ability to swim and decorate are not primarily caused by the dementia but also by other health conditions like Alan's poor mobility and the ulcers on his legs.

Danger of Health Conditions

Sometimes the health conditions can cause additional risk of harm or even dangerous situations. In the case of Alan his loss of appetite caused by the dementia increases his risk of becoming dehydrated and becoming frailer and less able to fight off the returning chest infections associated with his COPD.

Experience Health Services and Health care

Access to Health Care and Services

Two kinds of accessibility to Health Care and Services are mentioned by Jane and Alan; socio-economic and physical accessibility. They are not very mobile, Alan lost his ability to drive and Jane can't drive a car. Alan can only walk small distances, they have a wheel chair but even going out with the wheelchair can be difficult. For example, they only live a street away from the church and they do have a wheel chair but they still can't make it to church every day anymore. When they go to appointments in the hospital or clinic they have to go by bus or taxi or their daughter has to take them. Their daughter works so they are regularly dependent on taxis but taking a taxi is expensive for them.

Not only taxis are expensive for them and limit their accessibility to it's use, Jane also comments how the NHS no longer provides gluten free products on prescription anymore. This means Jane has to buy these products in the supermarket, she tells me that the products are expensive, three pounds for a loaf. This way the price of certain products can constrain its accessibility.

Because their physical mobility is fairly limited they receive some health care services in the home. Their GP visits them at home, district nurses visit them for

example to give Alan his B7 injection and the physiotherapist comes to their house.

Contact with Health Care Professionals

They have much contact with health care professionals as Alan has to go to the hospital often and they receive multiple services at home. In general, they are not very positive about health care professionals on hospital wards. They feel like they should have more time and attention for the patient and treat them as persons not commodities. I will elaborate on this further when I talk about the experience of health care.

On the other hand, they seem fairly positive about the contact with the staff of the ulcer clinic, who they have known for years. They were also positive about the contact with the doctor that diagnosed the dementia. They seem to be a bit less positive about their contact with the GP as he sometimes cancels their house visit without letting them know. Nevertheless, they have regular contact with their GP and he is frank with them. He told Jane that Alan would likely die of one of his co-morbidities not from dementia and he suggested to put Alan on a palliative care pathway when he developed another chest infection.

Experience of Health Care

Alan goes into hospital regularly. Jane and Alan have a long history of using health services. Alan comments on going into hospital fifty years ago for a lung operations and he has been going to the ulcer clinic for over thirty years now. He has been admitted to the hospital multiple times over the last couple of months for a stay between three and eight days. They say they don't question it when the doctor tells them he has to be admitted to hospital. Being in the hospital has become part of life for them. Alan accepts going to hospital as part of the day to day reality.

Denise *"So um you, you go to the hospital quite often, right? Um like how you feel about that?"*

Alan *"What could you do about it? If they say, you're called into hospital, they either don't call, you say, oh…"*

Jane *"No, darling".*

Denise *“Mm-hm”.*

Alan *“But no, you’ll go the best place when you’re called in”.*

Jane *“When you’re going in, yeah”.*

Alan *“You don’t argue about it”.*

Jane *“No, just…”*

Alan *“I just go”.*

They not only not question the doctor when he or she tells them that Alan has to be admitted to hospital. Health care staff also advises them on day to day activities in general. Jane and Alan were told that Alan wasn’t fit enough to travel to the funeral of his sister in the south of the country. Jane and Alan accepted that advise and decided not to travel.

They accept the authority of health care providers but criticize the care and services they deliver. In general, they feel like there is not enough eye for the “person” in health care. Examples are: bad communication in the hospital, delay of discharge. The hospital telling them that they couldn’t bring their own blanket. Not enough attention for the patient. They didn’t experience the “dementia friendly” ward as being “dementia friendly”. Also, health care professionals seem not always be aware of the co-morbidities of the patient.

Jane: “Because they’re not a commodity, they’re a human being in that bed”.

The lack of time and attention that Alan and Jane experience on the ward is also expressed in the fact that Alan doesn’t dare to drink much in the hospital being afraid to wet the bed. The health care staff sometimes makes him wait too long when he asks for help to go to the toilet. Not only have they experienced a lack of attention and time but also a poor exercise of health care. They gave the example of a care assistant who was asked to replace the bandage on the legs of Alan. According to Jane and Alan she clearly lacked the qualification or experience to do so. She replaced the bandage the wrong way causing his ulcers to bleed again and leaving Alan in a lot of pain. Alan also complains about the food in the hospital. He doesn’t like the food this problematic because he already has a loss of appetite and has had

a lot of weight loss lately. In the ulcer clinic one of the health care staff showed her concern about Alan's weight loss and used the metaphor of a car. She asked Alan if he would drive around his family in a car if he knew that he almost ran out of petrol. Alan said no. Then she continued and said that his body was like that car, he needs to eat and drink like putting petrol in a car.

The following fragment from my field notes summarizes well how Jane and Alan feel about the health care on a hospital ward:

Alan also told me he didn't like the ward, it was like a glasshouse and drafty (cold & windy). On top of that he didn't like the food, it was curry, he doesn't like curry. Jane brought him a sandwich. What he also didn't like about the hospital ward was that the nurse woke him up at 5.30 in the morning to tell him that he could use the bathroom because it was free at that moment. Jane told me she thought the nurse must have noticed Alan was awake so suggested he would use the bathroom. He was at the general geriatrics ward; many people stay there who have multiple health conditions including dementia. The ward is supposed to be 'dementia friendly' but Alan and Jane don't experience is as such. They said, they do their best there but is really not so good. The next day Wednesday around tea time Alan was already sent home.

Experience of Services

They seem to feel more positive about their experience with services. They mention all the assisting tools they got from social services, they are happy with the physiotherapist and the services of Age UK they used.

The services of Age UK were recommended to them by a neighbour who works for the organization, because of this personal tie they feel like Age UK is a safe and trustworthy organization. They are also members of a friends together group of the Alzheimer's society which they seem to enjoy.

Although they seem happy with the services they receive from non health care providers Jane does comment that she would not want to have care assistant coming to the house to help out. She feels like they would not be able to give the same care as she does (I discussed this in the section caring practice/external help).

Now we have discussed daily life as the couple experiences it we should also take a closer look at the individual who experiences daily life. I will do so by discussing identity of both spouses in the following section.

Identity

Identity Alan

Selfhood

Social Identity

His social identity is mostly build around how he used to help out people. He used to decorate people's houses, walk the dog of their daughter. He still is a godparent to the children of some nieces and nephews. They still acknowledge this role as is shown in the photos of the photo diary, two of his nieces and their daughters came to visit him and Jane. There is also Danny from church who looks at Alan as being an expert at knowing music.

Embodiment

His identity of being a worker is still embodied. He has lost a lot of weight and much of his mobility but the physiotherapist noticed that he still had a lot of strength. She asked him if he used to do manual labour in his working life.

Although the physiotherapist can recognize the strength in his body his overall appearance doesn't support this view. As you can see in both image 1 and 2 Alan looks frail because of his weight loss.

His bodily movement also makes him look frail. He gets tired very quickly; he can't talk longer than twenty minutes and can't walk very far anymore. He is also difficult to understand as he can't speak loud anymore as his COPD makes it difficult to get enough air. He needs help with very basic body movement like changing seats as illustrated in this fieldnotes:

Jane asks Alan if he likes to change to the other seat. She helps him up and to the other chair while he already sits down she takes his special cushion and asks him to get up again so she can put down the cushion than she asks him to bend forwards

so she can put a cushion behind his back for support. He makes jokes while Jane is reinstalling him.

His body and the co-morbidities seem to make it difficult to embody his identity and interests. He likes listening to music but is going deaf and his hearing aid doesn't fit anymore because he lost a lot of weight. He used to go to mass everyday with his wife but the combination of health conditions make him too tired and unable to walk a street and a half anymore. He used to go swimming but the ulcers on his legs prevent him from going swimming. He used to decorate people's houses but can't do that anymore. He used to enjoy reading but dementia makes it difficult to read books.

Some other parts of his identity he can still embody at least partly like being a dad. He can still show interest in his daughters live and do activities together like listen to music. He can also till be a friend to Danny from church and talk about music with him, as long as those memories stay with him. Talking can be difficult with the COPD but at least he can talk for small amounts of time.

He can still be a husband of Jane by acknowledging their marriage, for example when he recalled that they only needed two more years of marriage to get a golden egg. But some other aspects of his role as husband he can't carry out anymore like doing some tasks in the house.

Jane plays a role in enabling Alan to embody part of his identity, for example she buys him his cloths and she enables him to stay an active member of the family by arranging family visits and activities.

Gender

Alan made no explicit references to his identity of being a man. Jane also made no specific references to being a woman. This couple seems to have had quite an equal relationship, they both worked their whole working live and decisions were made by the both of them together. Jane has always done the cooking but that is also because she enjoys cooking. Alan used to do the jobs in the house and be a handy man, decorating people's houses.

Jane manages their social network which is often considered to be a female role. I need to read more on gender to say something about this. I would like to go

further than just ascribing certain roles and tasks to a gender stereotype or expectation. I don't find that a very useful analysis as it will only confirm a status quo. I found some relevant literature and will catch up on some reading on the topic and come back to gender[33].

Emotions

Alan seems to be frustrated with his health conditions but he does still have his humour and likes to make jokes. I don't know if he also used to joke a lot before he became ill, otherwise it could be a coping mechanism to deal with illness. Jim likes to Joke about drinking. He actually can't drink because of his medication and according to Jane he never used to be a big drinker:

Alan: "Shut up and drink your gin".
"I don't like tea I rather have Guinness".

Some experiences were emotional for Alan like his sister passing away. Some memories also make him feel sad like the memory of their foster child Matthew who ended up on the street a couple of years after he was send back to his mother. Jane and Alan also seem to be a bit sad about the fact that their daughter and son in law can't have children. But on the other hand, they are happy to their extended family has asked them to be godparents.

The experience of having foster children in general are emotional. Of some of the children it was emotional to hear how they had been treated at home before they came into their family. They do acknowledge that they learned a lot about people by fostering.

Identity Jane

Carer Identity

Both the practice of practical caring and the monitoring of health conditions and bodily functioning put the person caring out these tasks into a caring role. Caring out the role of caring comes with the identity of being a carer. Although these two are

[33] Eventually I did not have the time to analyse gender the way I would have liked so I decided not to analyse and discuss it in detail in the thesis.

connected the person caring out the caring tasks can choice to actively acknowledge and even own the identity of “carer” or resist this identity and ascribe the tasks to another role like being a spouse.

Jane doesn’t specifically refer to herself as carer when she describes the caring role she carries out. But she does acknowledge that she does caring tasks even when Alan is in the hospital:

Denise: *“And do you feel like when, when you go into hospital that um you ha- you kind of feel like you have to keep reminding the staff of everything?”*

Jane: *“Yes”.*

Denise: *“And kind of trying, yeah still to be the carer and err like both… Yeah”.*

Jane: *“Yes, and saying what’s, what’s not, what’s not happening now that should be happening. I point it out to them and say…”*

Denise: *“Okay”.*

Jane: *“… not in an argumentative way…”*

Social Identity

Jane has multiple social identities, the spouse of Alan, the carer of Alan, the neighbour, a member of the church. But most of all she seems to identify with her identity as a family member, especially mother. She and their daughter talk to each other every day. She receives help in the home and with the care from family members.

Personal Identity

She identifies with being a catholic, Alan’s wife, a mum, a godmother, a friend and a neighbour. As described above she doesn’t identify with being a carer herself but she does identify that she fills in the carer role.

Embodiment

The caring tasks that she carries out are the embodiment of her identity as being a carer for Alan. Her health conditions also sometimes make it difficult to embody part of her identity. Her osteoporosis makes it difficult to do tasks in the household and she needs the help of her cousin to do the household tasks.

Gender

Jane also made no specific references to being a woman. This couple seems to have had quite an equal relationship, they both worked their whole working live and decisions were made by the both of them together. Jane has always done the cooking but that is also because she enjoys cooking. Alan used to do the jobs in the house and be a handy man, decorating people's houses. Jane manages their social network which is often considered to be a female role.

Emotions

As noted before Jane holds some sadness and frustration about Alan's health conditions. She also finds it difficult to see a 'loved one' in the hospital. She copes with these feelings by emphasizing that she and Alan are a team: "united we stand".

A difficult moment for Jane was when the GP told her that Alan would not die from his dementia but of one of the co-morbidities. Jane didn't think Alan's health was so frail. When he caught another chest infection she didn't think that he wouldn't recover anymore.

Jane and Alan also seem to be a bit sad about the fact that their daughter and son in law can't have children. But on the other hand ,they are happy to their extended family has asked them to be godparents. They also share emotions of sadness about their foster child Matthew who ended up on the street a couple of years after he was placed back with his mum.

The experience of having foster children in general are emotional. Of some of the children it was emotional to hear how they had been treated at home before they came into their family. They do acknowledge that they learned a lot about people by fostering.

Appendix 5 Publication Medicine Anthropology and Theory (MAT)

Boundaries in the home: Negotiating access in the field

Denise de Waal

How would I be able to understand their daily lives when they were only willing to show me their kitchen and carefully drew boundaries around what they liked to talk about? I only had six months to do fieldwork; would I be able to establish a level of rapport to be considered an 'insider'?

My research looked at the daily life experiences of couples when one has dementia and co-morbidities and their partner is the informal caregiver. 'Entering the field' involved gaining permission to visit local community centres, dementia activity groups, and well-being cafes where I could talk to possible participants about my project. Once people showed interest in participating in the project I had to build rapport with them in order to negotiate access to their experiences, lives, and homes. But even after the couples had given their consent to take part in the project and I had been visiting them at their homes for a couple of weeks, I still felt like I was negotiating access.

I had been taught that gaining access is a time-consuming process. The rule of thumb seems to be: the longer you spend in the field the better the quality of your data will be (DeWalt and DeWalt 2010). Anthropologists have identified turning points in their research process, events that allowed them to move from the outside to the inside (Pitts and Miller-Day 2007). Kathleen M. DeWalt and Billie R. DeWalt (2010) point to Clifford Geertz's (1973) description of his attendance of a Balinese cockfight as a classic example of this. But perhaps, instead of seeking out such turning points, we should look at the back and forth of negotiating access as a valuable and informative process in itself.

Getting to know Hamid and Aaisha[34]

When I arrived, Aaisha and Hamid greeted me, and Aaisha invited me to sit down on the couch. When I explain the project to them, Aaisha said: 'I think it is strange you like to know all these things about people. You like to know these things so you can help people, right?' I explained that I would also like to share the outcomes of this project with service providers so they could consider how to improve their services.

After our first visit, Hamid and Aaisha decided to take part in the project, and signed the consent forms. For our subsequent weekly visits, Aaisha asked me to call them before every visit so she could confirm the appointment. She also repeatedly asked me questions about my family, personal beliefs, and lifestyle: 'Are you married? Does all your family life abroad? Are you religious? Do you go to church? Do you cook meals? What type of meals do you cook?' The answers never seemed to satisfy her, as after one question another always followed.

I wondered whether she was testing me by always asking me these questions and requesting that I call her before every visit. Was she checking if I was trustworthy and whether I would keep my word? I learned that in the past she had had a difficult time contacting service providers. They would sometimes promise to visit or ring her back without doing so. She also elaborated in one of our interviews about how she has been trained to be a good housewife and housekeeper; these comments told me that the home was an important space for her, one that she saw it as her domain. It was a place that she cared for and for which she felt responsible.

[34] All names are anonymized.

This feeling may have grown even stronger, now that she was the main caregiver for her husband and their life revolved around their home.

I felt like I was stuck being an outsider: I had to keep negotiating access to their home and life, which depended on Aaisha's approval. But I also began to understand what the home meant to her and how she decided whether I was a trustworthy interlocutor based on her past experiences and the values that were important to her.

The feeling of being in the space between inside and outside continued, even when I was allowed into the home. In particular, the way that Aaisha set clear boundaries regarding which part of the home they would allow me into showed me that I was not yet fully trusted. Our visits only took place in the kitchen or outside of the home. Hamid once offered to show me more of the house but Aaisha stopped him. The boundaries Aaisha kept regarding their home also became visible in the photos they took as part of their photo diary. I asked all of the participating couples to take pictures of subjects or objects that were part of their daily routine. Hamid and Aaisha's diary only contained pictures taken in the kitchen except for one picture of their TV in the living room. Furthermore, they chose not to give me permission to publish the pictures.

Home is closely related to who we are. It plays a role in our experiences and is a bearer of our identity as it stores objects and memories that symbolize part of our identity (Chaudhury and Rowles 2005). We only provide people access to our home when we feel comfortable sharing with them who we are. How people set boundaries for health care in their home is a pertinent example of this, as they will decide on which rooms health care professionals can enter and which interventions and treatments can take place in those rooms (Twigg 2006).

In my research, Aaisha's boundaries told me that she considered me to be an outsider, and this was possibly influenced by her past experience with support workers. In health studies research this is a known phenomenon and McKillop and Wilkinson (2004) advise researchers to take into consideration past experiences participants might have had with service workers entering their home. Hamid did not have an active role in the process of negotiating these boundaries; Aaisha was the decision maker, and perhaps she took up this role because of Hamid's dementia. In such couples, decision making usually shifts to or stays with the caring spouse

(Samsi and Manthorpe 2013). It is also possible that Aaisha was always the decision maker on who had access to the house, in connection with her role as homemaker.

At first, I felt frustrated, insecure, and a bit worried about the ongoing negotiation. But eventually I realized that this ongoing process over access to the home and their lives provided me with a rich source of data. It gave me insight into their values, past experiences with services, the importance of their home, and the dynamic between the couple (Bjørnholt and Farstad 2014). Reflecting on the process of gaining access and the status in the outsider/insider dichotomy has provided me with useful information about how our interlocutors manage social relationships and draw boundaries. As anthropologists, we can learn a great deal if we approach negotiating access as an important source of data instead of a challenge to be overcome.

References

Bjørnholt, Margunn, and Gunhild R. Farstad. 2014. "'Am I rambling?' on the advantages of interviewing couples together." *Qualitative Research* 14 (1):3-19.

Chaudhury, Habib, and Graham D. Rowles. 2005. "Between the Shores of Recollection and Imagination: Self, Aging and Home." In *Home and Identity in Late Life: International Perspectives*, edited by Graham D. Rowles and Habib Chaudhury, 3-18. New York: Springer Publishing Company.

DeWalt, Kathleen M, and Billie R DeWalt. 2010. *Participant observation: A guide for fieldworkers*: Rowman Altamira.

Geertz, Clifford. 1973. *The Interpretation of Culture: Selected Essays*. New York: Basic Books.

McKillop, James, and Heather Wilkinson. 2004. "Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed." *Dementia* 3 (2):117-125.

Pitts, Margaret Jane, and Michelle Miller-Day. 2007. "Upward turning points and positive rapport-development across time in researcher—participant relationships." *Qualitative Research* 7 (2):177-201.

Samsi, Kritika, and Jill Manthorpe. 2013. "Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers." *International Psychogeriatrics / IPA* 25 (6):949-961.

Twigg, Julia. 2006. *The body in health and social care*: Palgrave Macmillan.

About the Author

Denise de Waal is a final year PhD student in dementia care at the University of Bradford. In her current project she looks at the daily life experience of couples of whom one has dementia and co-morbidities and the partner is the primary carer. She uses interpretivist ethnography and spend six months paying weekly visits to five couples in the community in North England to do fieldwork.

Appendix 6 List of Dissemination Activities

6.1 Conferences

6.1.1Presentations

‘“Isn't it nice that people call us here? We don't even live here”: The sense of home in later life for people living with dementia and their spouses’, paper presented at the 15th EASA Biennial Conference, ‘Staying Moving Settling’, at Stockholm University (14-17 August 2018).

‘Using photo diaries as a participatory approach in spouse care research: The case of people with dementia and their caring spouse’, paper presented at the BSG 46th Annual Conference, ‘Do Not Go Gentle: Gerontology and a Good Old Age, The Art of Ageing’, at the Centre for Innovative Ageing, University of Swansea (5-7 July 2017).

‘Using habitus to seek insight in the experience of caring for a person with dementia at home’, paper presented at the session ‘The Continuing Importance of Bourdieu’ at the British Sociological Association (BSA) Bourdieu Study Group’s Inaugural Biennial Conference, ‘The Contemporary Relevance of the Work of Pierre Bourdieu’, at the University of Bristol (4-6 July 2016).

‘Capturing the daily life experience of couples caring for and living with dementia and co-morbidities in their own homes: Photo diaries’, paper presented at ‘Dementia and Everyday Life: Creative Approaches’ event. It was co-hosted by the Morgan Centre for the Study of Everyday Life, the Dementia and Ageing Research Team and MICRA, the Manchester Institute for Collaborative Research on Ageing (7 April 2016).

6.1.2 Panels

‘Staying, moving, (re)settling: Transitioning practices, actors and places of care in later life [Age and Generations Network]’, Staying Moving Settling, 15th EASA Biennial Conference at Stockholm University (14-17 August 2018). Co-convener (with Dr Matthew Laviere, University of Sheffield).

6.2 Invited Talks

6.2.1 Academic

‘Ethnography as a method to understand the daily life experience of people with dementia better’, at the DZNE (German Centre for Neurodegenerative Diseases) at the University of Witten/Herdecke, Germany (6 June 2018).

‘“You are sitting there, aren’t you, love?” Transitions and loss: Spousal care for people living with dementia’, Medical Anthropology Research Group, Institute for Medical and Social Anthropology, at the Freie Universität Berlin, Germany (26 April 2018).

‘Exploring the quality of life for people living with dementia and co-morbidity living with their spouses in the community’, Long-Term Care and Dementia Research Group, Institute for Social Science, at the University of Amsterdam, The Netherlands (16 March 2017).

6.2.2 Public Engagement

‘Daily life with dementia and other health conditions in the community’, presentation at the Robin Lane Wellbeing Centre, Pudsey (7 June 2017).

6.3 Publications

6.3.1 Accepted for Publication[35]

De Waal (2018) Boundaries in the home: Negotiating access in the field. *MAT Medicine, Anthropology, Theory*.

6.3.2 Articles to be submitted for Review and Publication[36]

De Waal, Small, and Downs. Using Bourdieu to deepen understanding of spouse care in dementia.

De Waal, Small, Downs. The paradox of using photo diaries as a participatory research method for people with dementia.

[35] Had not been published yet at the time of thesis submission.
[36] We have not decided yet on which journal or when to submit

6.4 International Exchange

Visiting PhD student at the Institute of Social and Cultural Anthropology, Medical Anthropology Research Group, at the Freie Universität Berlin (16 April-30 June 2018),funded by Erasmus+.

Visiting PhD student at the IQ Scientific Centre for Health Care at the Radboud University of Nijmegen (16-18 October 2017), funded by University of Bradford Doctoral Training Centre.